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RESOURCE CENTRE FOR MENTAL HEALTH CONSUMERS

Program and resource book

Consumers as Educators,

Friday November 11th, 2011, 9am – 5pm

Karstens, 123 Queen St, Melbourne



Auspiced by:



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Consumers as Educators, Friday November 11th, 2011

The primary purpose of today is to bring together a critical mass of people interested in “consumers as educators” to share, network, debate, engage, etc. The day has been organized with some principles of an “unconference” in mind. That is, it is assumed that *all the participants* have a great deal to contribute to the day – it’s not intended to be a top-down information transfer, with a relatively passive (and possibly bored!) “audience.” With this in mind, we have tried to keep much of the time open for questions, answers and dialogue.

The “Brag and Steal” sessions: These are an opportunity for some leaders in this area to showcase their work, briefly, followed by ample time for discussion.

Panel discussions: These panel discussions have left very open, and will be shaped by the concerns participants bring to the day, and what emerges from discussions on the day.

Workshops: There will be many workshop options available and we encourage participants to put forward workshop ideas that they are keen to workshop. In this way, we hope the conference is as relevant as possible for your needs.

Time slot	Session	Speaker
9:00 – 9:25	Housekeeping + Intro to the day	Flick Grey
9:25-10:25	Brag and Steal #1 (+30 mins Q&A)	Merinda Epstein and Noel Renouf, Ann Tullgren, Brenda Happell
10:25 – 10:45	MORNING TEA	
10:45 – 11:30	Keynote: History of consumers as educators	Meg Smith, Simon Champ, Merinda Epstein
11:30 – 12:30	Panel What are the major issues and challenges today?	Brenda Happell, Noel Renouf, Merinda Epstein, Sandy Watson
12:30 – 1:30	LUNCH	
1:30-2:30	Brag and Steal #2 (+30 mins Q&A)	Sandy Watson and Kath Thorburn, Wanda Bennetts and Bill Moon, Cath Roper
2:30 – 3:30	Workshops (4 spaces available)	
3:30 – 4:00	AFTERNOON TEA	
4:00 – 5:00	Panel Where to from here?	Cath Roper, Ann Tullgren, Lyn Mahboub, Kim Koop, Ellie Fossey



Introduction:

This collection of resources, reflections, history, practical tips and deep analysis, was collated for Our Consumer Place's one day symposium on Consumers As Educators, November 11th 2011.

This collection is an eclectic snap-shot – it contains some absolutely brilliant material, but it is in no way intended to be comprehensive, representative or authoritative! There is also some overlap between different contributions. The predominant focus is on mental health consumers educating clinicians. The reasons – historical, political and expedient – for this emphasis will be explored during the symposium.

It is compiled in response to our observations that:

- much of our history has been lost, so we (and services!) often act a-historically,
- many intelligent, inspired and profoundly useful resources are under-utilised, or little known,
- many of our brilliant ideas and resources are lost in backrooms or the dusty shelves of libraries,
- many consumer teaching opportunities are “leaf work” – isolated, one-off, inclusions – rather than “root work,” which would lead to deeper, transformative learning and systems-change (see the article on the *Lemon Tree Project* for an explanation of this crucially important concept).

This collection is a *beginning* to changing this... Our Consumer Place intends over time to develop a more fully elaborated resource.

One last note: The material in this collection has been generously shared by various consumer educator leaders (sometimes in collaboration with dedicated and politically-aware non-consumer allies). Feel free to use, share and adapt these materials, but we ask that you reference contributors where and when appropriate. Much of this material is in a draft form, and will be made available in the future on the Our Consumer Place website (www.ourconsumerplace.com.au).



-Flick Grey and Merinda Epstein, Our Consumer Place



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Learning Together: The Deakin Workshops

Education and Training Partnerships in Mental Health¹

Introduction²:

The process of this project is both glorious³ and notorious in that certain forces felt it was too far before its time to allow publication (*Learning Together: Education and training Partnerships in Mental Health*) to be endorsed by the government that funded it.⁴ For the purpose of this short piece I'll look at why this anomaly might exist by looking at history, underlying assumptions, process, experiences and product from a consumer perspective.

History

The history to the Deakin Workshops is of interest only as it explains the context in which it emerged. I sat on the Commonwealth's Steering Committee charged with developing a mission brief to progress a project which would look at the skills, knowledge, education and training of the mental health workforce Australia-wide. The Steering Committee was plagued by our own appalling choices and divisions between us which led to two hopeless attempts at deliver us something useful before we hit upon Deakin consultants to undertake this task. We commissioned KPMG⁵ consulting for the first project and they managed to alienate not only consumers and carers but also most of the clinical groups.

By the time Deakin Human Services came along we were very aware of the potential hazards of bringing consumers and carers as well as clinical groups together in such an ambitious project. For this reason we made the stipulation that consumers and carers should be chosen as independent experts in education but that the clinicians, wherever possible, should represent their various constituencies. One of the reasons this is so interesting in 2011 is that 13 years after The Deakin Workshops took place consumers are now being constantly asked to "represent" (non-existent) constituencies, but the clinicians at the same table are there for their expertise!

Underlying assumptions: Critical Mass of consumers

In her introduction Dr Jan Carter writes (p.4):

¹ Prepared by Deakin Human Services Australia with funding from the Commonwealth Department of Health and Aged care under the National Mental Health Strategy, February 1999

² From a consumer perspective this project is too big and too important to do it justice in a few pages. It is still available on the National Mental Health Strategy and I recommend that if you are interested you download a copy and read it. It's not long – only 57 pages.

³ When I use the term 'glorious' this does not mean there were things that can't be criticised. For example, there was a bringing together of consumers and carers that was less than helpful. There was also a strongly articulated definition of consumers as those with 'Serious Mental Illness' a term that we critique and was being critiqued in 1997-8, and only the clinical workforce was involved. The last two decisions are described by Dr. Carter as needed to define the project in a way that would make it workable.

⁴ "The opinions expresses in this report are those of the authors and not necessarily those of the Commonwealth Department of health and Aged care.

⁵ Learning Together: Education and Training Partnerships, 1999, p4



"An early decision was made that a critical mass of consumers and carers needed to be involved. The Advisory Committee to the Project agreed, so there were at least as many consumers (and at least as many carers) as there were representatives of any one of the five disciplines. If consumers (and carers) were to be given a voice in the project, the size of their delegation needed to be adequate. So for this reason six consumers, six carers, joined the six psychiatrists, six psychiatric nurses, six psychologists, six occupational therapists and six social workers invited to the initial workshop."

Respect for the relative of power of different discourses

A weekend before the official start of the process a weekend was offered to consumers and carers. They would meet separately and then come together to develop the overriding 'statement of principle' that would then drive the following workshops. The priority was given to consumer and carer knowledge and opinions. They were to be seen as 'knowledge' and not 'perceptions' and consumers from around Australia would get a chance to strategise.

Defining the Guiding Principles:

After an extended process of discovery it was decided that the future test for mental health professionals of quality and effectiveness of any educational and training process would be based on two guiding principles. These stress that mental health professionals would:

1. Need to learn about and value the lived experiences of consumers and carers; &
2. Recognise and value the healing potential in the relationship between consumers and service providers.

Process

The process was, simply (but it wasn't really simple at all actually!!) a series on 9 workshops. The workshops lasted for a weekend and they were held at ANU where we could all stay and work together in a nice environment.

The consumers and carers met together (separate from each other) to meet the Deakin staff, to 'embolden' ourselves and, for some, to meet for the first time consumers from other States and Territories and try and work out what we collectively needed and how we might get there. Julie Shaw and I taught all the consumers how to use the Lemon Looning game (see page 47). Consumers and carers also spent considerable time developing what became the 'statement of principle' for the whole series of encounters. ie:

"The relationship between consumers and service providers and carers and service providers, should be the primary focus in practice and research in mental health. Consumers and carers are therefore major players in the education, training and development of the mental health workforce. "



In the first full workshop, all the clinicians and clinical educators were asked to take part playing Lemon Looning. This was part of the Deakin team's determination to view consumer perspective as central and also about the principle of reducing the power difference between different workshop participants.

In the first full workshop there was some debate, but the consumer and carer 'Statement of Principle' was adopted by everyone present regardless of which clinical group they represented. Some clinicians, especially psychologists and psychiatrists, were challenged by this starting point. There were also differences within each of these groups. But the goal was to get it through and this was achieved.

Over the next few workshops it was agreed by everyone that; "the beginning point of understanding mental illness needed to be about learning about the experiences of people who are mentally ill... going well beyond the workshops".⁶ It was agreed by everyone, after some debate, that this would mean that the beginning point of any training would no longer be:

- Knowledge about the brain and biological views about mental illness; and/or
- Psychodynamic theories of causation of mental illness; and/or
- Behavioural interventions in mental illness; and/or
- The social factors antecedent to or consequent on mental illness.

*"Important as these ... are they are secondary to meeting a person face to face, in an honest, committed effort to understand this experience. It was agreed that inherent in this meeting is a potential for a healing relationship."*⁷⁻⁸

One of the main processes that made this a particularly interesting set of workshops was that there was a professional medical educator present and it was his job at the end of each day of each workshop to give feedback to the group points of interest and importance, not in terms of substantive issues but rather in terms of pedagogical theory, process and ongoing needs of clinical educators. This was something the consumers had been calling for.

There was a strong attempt to keep the group of 35 (five people from each clinical group and five carers and consumers) as stable as possible. This was quite difficult but Dr Carter's reputation for running a tight ship helped the process considerably. There were, however both avoidable and unavoidable changes during the duration of the workshops.

Another process was to sometimes have consumers and/or carers as process watchers when the clinical groups were meeting alone. The reason for this was

⁶ Learning Together: Education and Training Partnerships on Mental Health 1999.p5

⁷ Learning Together: Education and Training Partnerships in Mental Health 1999, p. 5

⁸ It would be good to go back in time to 1998 when this report was written and suggest that the assumption ought to be that the healing might go both ways.



twofold. One was to do with upholding our authority with the Deakin people recognising that this had to be reinforced or the power relationships would keep bouncing back to the status quo. The other reason was important to was to try and break the pattern of the different clinical groups blaming each other for all the problems with the system and/or joking at the expense of other clinical groups. Being part of this taught me that it is a folly for consumers to get cheap laughs by setting one clinical group up against each other in our work. It's an easy trap to fall into because it feels good to get a laugh but it's at everyone's expense.

Experiences

1. I don't think any of us found the Deakin Workshops easy. They were often emotionally charged and despite the fact that we got to know many of the clinicians and academics very well many people, particularly from psychology and psychiatry, found the amplification of our voice very hard to handle. They were used to having power and the way these workshops were constructed they weren't asked to come and 'lecture us' as they expected was their right but rather to sit and listen to us, which they had not expected at all.
2. Psychiatrists, not unsurprisingly, voted with their feet and just refused to come. It's worth saying that Graham Martin and Alan Rosen stayed on to the end and then wrote the psychiatrists' chapter in Learning Together. I know it was difficult at times for both of them because they felt under siege when it wasn't their personal practice that was being criticised. This is a familiar story from other projects including and especially the Understanding & involvement (U&I) project (see page 29).
3. There were other clinical groups who really got into the process and the attrition rate was much lower. There could be some very interesting lessons to learn from this and they have a lot to do with power.
4. At one stage there was a consumer walk out. We were serious. We did not come to these workshops and intend to go away empty handed. The walk out was a result of Deakin setting up a situation where the consumers (and the carers) were restricted from being part of the decision-making. Later we got an apology.
5. We didn't like seeing some of the other participants get so stressed but we knew it was the only way to go forward. Comfort doesn't bring change. Discomforting exchanges are part of the business of making the clinicians and services we deserve and expect – if this is indeed possible.
6. Over the many weekends we met we really got to know people and this made it even harder to upset them and we didn't set out to hurt anyone. However, coincidentally, we know we did.
7. These workshops were very serious affairs. They meant questioning taken for granted assumptions about everything from what professionalism might or might not mean down to listening to people talk about the harm that had



betrayed them when it came from a treating clinician who was someone they respected. Indeed there was a really interesting discussion I remember where people were talking about how the 'good egg' practitioner can actually do the most harm because trust is, accidentally, abused.

Product

1. The official product is the book; *Learning Together: Education Partnerships in Mental Health*, which each group (consumers, carers, psychiatrists, psychologists, social workers, occupational therapists and psychiatric nurses) wrote a chapter of, and these make fascinating reading. The psychologists struggled a little. The chapter from consumers is primarily written by Daniel Rechter with some help from me.
2. Dr Carter's introduction and forward could have been used as a great working tool for consumers because it is strong and forthright about important issues that give our knowledge worth. It's unfortunate that it does consistently talk about 'serious mental illness' and 'consumers and their carers' – two terms that I can't stand. We can't use date as an excuse. The critique of these terms was well underway in 1998.
3. This book and the extremely hard work it represents is still relevant and could have been strategic if only the various clinical lobby groups hadn't persuaded the Government not to endorse it. Such a pity.
4. There was also a problem of this project being 'too out there' for conservative clinical associations who were scared by the process and the report. This meant that although the workshops often totally convinced the actual people who took part, these representatives were unable, in the end, to bring their institutions along with them into a new way of thinking and being in relation to consumers. Another great pity.
5. The most important thing to have come out of these workshops is us. When I say us I mean the collective us, not just consumers. There were educators, clinicians, carers as well as consumers who stayed with this difficult process, rode the emotional humps, got hurt and laughed together, learnt heaps from one another and changed and grew as part of the process. Out of these unofficial affiliations many ideas have grown and projects have started. These are a joy. There are many, too many to include but three examples have been the creation of the Consumer Academic in the Centre for Psychiatric Nursing at Melbourne University, the collaborative work with the University of Tasmania Social Work Department, La Trobe Social Work and now the Social Work Department at the University of Queensland.

AN ACTIVITY TO START SESSIONS



I've used this activity several times now and the response is extremely positive. I use it at the start of teaching in the mental health subject.

I have a large collection of postcards – the free cards you can pick up at trendy cafes. I spread these over a large table and ask the students to look them over, and then pick out 2 or 3 which they can show the class which illustrate where they stand in relation to mental illness at the beginning of the subject, and 2 or 3 cards which illustrate where they want to be by the end of the course.

The students take the cards back to their place and I go around the class inviting each student to introduce themselves and to talk to their cards.

The exercise helps break the ice as some of the cards are quite humorous. Students tend to feel very comfortable and often disclose personal/family experiences with mental health difficulties, as well as their fears about the topic.

The discussion about where they want to be by the end of the class in relation to mental illness is a good way to find out what they may know already and what their learning goals are. This helps the educator personalize the course. I record responses on the whiteboard and then at the end of the exercise we plan the sequencing of topics to be covered.

- from Ann Tullgren



Training Staff

Some Principles Two Consumer Educators Have Found Useful

- ‘Use **the knowledge in the room**’: see what trainees know already so you know what is new.
 - Get people who know something talking to the other trainees – people learn best from their **peers**
 - If there are **two** ways of making the **same** point, choose the **positive** one
 - But **also** be **honest**, and say the **hard** things when needed
 - Demonstrate **respect of the staff’s experience**
 - Then give staff a chance to ask questions of consumers outside a clinical relationship and hear **our** experience
 - **Varied** methods for **varied** learning styles – people learn by listening, by doing, by seeing – **have** some of each
 - **Varying** the **pace**, and varying **activities** to keep interest
-

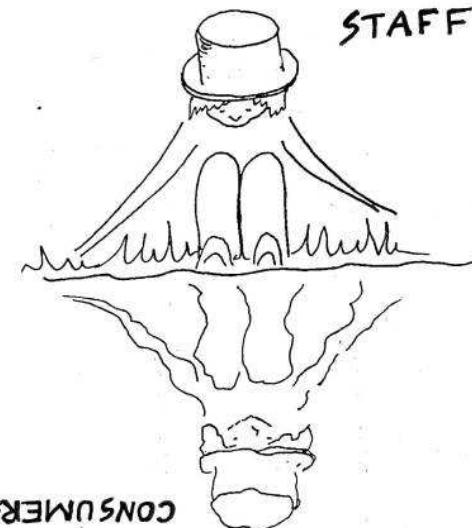
And most importantly: Have Fun!

- From Wanda Bennetts and William Moon



EXPERTISE: EMBRACE OR EXCLUSION?

Place Merinda's cartoon in front of each student, drawing facing the desk top.



Questions for discussion

- How have you placed the cartoon on your desk?
- Which is uppermost: worker or consumer? Why?
- Examine the binary, worker/consumer: workers can be consumers/family/friends and vice versa?
- What sort of relationship between worker and consumer would you like to see? How could each attend to the other?
- What are the impediments to the construction of this relationship?
- How is the professional gaze constructed?
- How can the practices of observation, measurement, treatment, recording, case conferencing, evaluation (all technologies of power) can silence the voice of the person with mental illness and distort the relationship between professional and patient?
- How does the agency charter influence how you attend to the lived experience?
- Why is the drawing of the consumer blurred? Is the consumer less whole? Or, is the consumer blurred because of the perceptions of the worker?
- How can the consumer become less blurred?
- What of the outline of the worker?
- Where does expertise lie? What kinds of expertise could exist?

Exploring an ethic of care

- What is your ethic of care and your practice model?
- How do you propose to 'grow' your ethical imagination?
- How does your ethic of care influence your relationship with your clients?
- What factors might influence you to think or behave in a way that is in conflict with your ethic of care?
- How could you manage these conflicts?



DRAFT of a HELPSHEET from Our Consumer Place

Education of the mental health workforce

One for the books – moving from the learner to the teacher

The illiterate of the 21st century will not be those who cannot read and write, but those who cannot learn, unlearn, and relearn. - Alvin Toffler

Introduction

Moving from receiving psych. education from psychiatrists and other clinicians working in mental health to being the educators is an exciting and important shift in the way consumers are perceived by mental health professionals and in the way they see themselves.

Power

When moving from ‘the one who needs to learn’ to ‘the one who has expertise and knowledge’ there is a critical change in the power dynamics.

History

In the 1990s clinicians and bureaucrats could not perceive of this shift in expectations of power. Every time the idea of ‘*consumers as educators of clinicians*’ came up it would quickly get twisted around to; ‘*what consumers needed to be taught first*.’ Incredibly, they talked about this language manipulation as reflecting a ‘consumer-centred approach’. *The other response was commonly, “Oh! It’s a great idea! Consumers can do the psycho-education that other consumers need.”* It was incredibly frustrating. Gradually things changed:

- Consumers who happened to be clinicians (“two hats”) were tentatively let in the door, as were famous, non-consumer-perspective thinking public identities and a few of us with teaching qualifications;
- Consumer organisations became more involved (against professional resistance);
- Consumers were invited to present – first in social work and occupational therapy. They were usually asked to ‘tell their story’ in the final session of a 6 week course. Many found that after they had left the room, students were encouraged to criticise the presentation rather than think about the issues. Gradually, these disciplines started to explore wiser ways of utilising the skills and knowledge consumers bring;
- Consumer educators started employing and working with a wide range of consumers. A dedicated consumer educator position at the University of Melbourne, School of Nursing, was created;



- Consumers started to take on more interesting, more dynamic roles with post graduate students;
- Psychiatry came on board, at first very tentatively but then more frequently and with less cynicism.

Ways of engaging in the education of clinicians:

- **Telling story** – Consumers often find themselves in a position of either wanting to tell their personal stories or being ‘drawn into’ telling their personal stories.
- **Lectures** – Giving a lecture to a group of people is a good way to get a lot of information across to a large group in a set amount of time. It creates distance, which may provide a safety net for some people, but may leave others wondering if they have connected with the audience.
- **Groups** – Providing education to people in groups provides an opportunity for some good reflective work to occur. It is a good way to engage people in discussion and work on particular tasks that can be set by the consumer educator. It can be hard work if you get participants who do not want to interact, so you have the feeling that you are ‘pulling teeth’.
- **Interactive workshops** – Interactive workshops are ideal if you want to provide an ‘experiential’ style of education that allows participants to put themselves in the shoes of another for a short space of time. This can provide some valuable insights for participants, although sometimes there can be resistance to this. There is a strong element of the unknown when running interactive workshops. Therefore, educators will have much less control over what comes out during the session and it is best to be well prepared for this.
- **Consumers working together** - It is strongly advisable that consumers work together when delivering training. This means that you can support each other. Importantly, it also means there is someone else with whom you can discuss how it all went at the end of the session.

This HELPSHEET has been written by Merinda Epstein for Our Consumer Place.



DRAFT of a HELPSHEET from Our Consumer Place

CONSUMERS AS EDUCATORS

The education of the clinical workforce

The following are some tips for consumer educators working in clinical settings:

- 1. Be honest and brave:** The most important skill is keeping true to the voices and experience of consumers, even if that requires presenting challenging information. If you need to do this, be sure to acknowledge the times when things are done well (if you know any!).
- 2. Speak to other consumers:** Speak to as many other consumers as you can to build up a good repertoire of knowledge that you can draw on and use as examples to illustrate your points. Clinicians respond well to examples and you can feel more confident if you have more knowledge. Real examples are hard to dispute or ignore.
- 3. Use the knowledge in the room** Mental health professionals have often a lot of experience of the psych. system, including concerns of consumers. Acknowledge this and draw it out, rather than act like you assume you think they have never considered consumer issues. Ask the trainees questions first, rather than make assertions – find out ‘what is known in the room’.
- 4. People hear things better from peers:** Information, especially about things that are problems or shortfalls of the system can be best heard coming from another trainee – a peer rather than a consumer ‘outsider’. Start out asking ‘what issues do you see regarding...?’ At the end of discussion, provide information about any missing issues.
- 5. Build Empathy and encourage people to put themselves in other peoples shoes :** Ask questions that require participants to put themselves in other people’s shoes. Do this by asking questions such as “What do you think consumers would say about...?” or “How might you feel if you had to...?”
- 6. Build on experiences which unite us:** Ask questions and propose parallels which show consumers acting as trainees would in analogous situations. ‘How do you feel when such and such happens in your daily life?’ Then relate this to the experiences of consumers.
- 7. People hear positives better:** Where it is possible to make the same point by praising good practice, it works better than constantly criticizing bad practice.
- 8. Have Fun!** Life’s too short to do anything else- and if people are laughing they are listening!



Sample Activity

Split participants into small groups. Provide each group with a scenario (e.g. a consumer on the inpatient unit is getting very restless and starting to feel quite angry). Ask groups to discuss what they would do in this situation and then get each group to present back. Provide your comments and insights to the responses.

At the end of the session, ask each participant to name one thing they would do differently in the future as a result of the session.

This HELP SHEET has been written by Wanda Bennetts, for Our Consumer Place.



Flick's reflections from the ground: teaching from a consumer perspective – by Flick Grey

Preface:

For nearly 2 years, I have been teaching from a consumer perspective (yes, I am fresh!). Previously, I had 10 years experience teaching undergraduate students in various liberal arts. I'm also trying to finish my PhD (although I am coming to understand, in my body, even more reasons why there are so few consumers who have completed PhDs ... but that's another story).

In some ways this has been a natural transition – my consumer-perspective work is grounded in fostering critical thinking, and paying attention to the political dimensions of our lives and the mental health system. In other ways, it has been a transformative transition – I now feel pushed to be even more self-reflective and transparent about my position in relationship to the material I am sharing, the role of lived experience and the complexities of identifying as a “consumer.” I am no longer able to position myself as neutral representative of omniscience, of disembodied “knowledge” (not that I ever really did that, but it’s a seductive position, and one that many students feel comfortable being taught from).

As a consumer-perspective educator, I have predominantly taught student clinicians, although sometimes I have delivered sessions in professional development contexts. My main clinical groups have been social workers and (less often) psychiatric nurses. There is also sometimes a cross-over between “teaching” and other activities I have been engaged in, such as presenting at conferences for a more general mental health worker audience, and writing for textbooks. Actually, as an “out” consumer – and one whose professional identity is a consumer thinker – my *life* seems to be full of teaching opportunities.

What this work fundamentally is about (for me)

I understand my work as being *a vehicle* for sharing the richness and depth of consumer-perspective thinking. I claim little credit for presenting individually original ideas, although, like all of us, I extend or push certain ideas here and there. My skill is more in organising and communicating a body of collectively-conceived ideas coherently and persuasively.

But most of my work is focused less on particular *content* than on encouraging a paradigm shift, a fundamentally necessary change in orientation – from clinicians-as-experts to consumers-as-experts. Consumers are the experts in our own lives, in understanding the mental health system (isn’t it meant to exist to meet our needs?), and in understanding what these experiences *are!* I say this not to dismiss professionally-oriented knowledge, but to reorient the centre of expertise into our bodies and minds.



In my mind, the role of clinicians is to support people's self-determination, not to exert their power over us (often disguised as benevolent helping, or expert knowledge, but really, it's largely about power).

In my experience, many of the people I teach find the material challenging. But it usually resonates with some intuitions inside them, and so they communicate that it is satisfactorily transformative learning. But of course, they work in a culture dominated by the clinician-as-expert paradigm, so I do wonder how much it "sticks," given much of the work I do is "leaf work" (see the piece on Lemon Looning, p.43). We are not usually in a position to structure the educational environment (yet ...?), but instead are typically an "add-on" or "another perspective". Even if we have power in a particular subject, the overall course/job/career tends to structure us as outsiders.

Opportunities vs priorities

My teaching opportunities have been *ad hoc*. They have not come about because of any particular skill or experience I have in specific contexts (indeed, in my own lived experience as a survivor/consumer, I have had *nothing* to do with social workers – except that many of my friends and all of my housemates are social workers, but that's a different story – and I've had comparatively little to do with psychiatric nurses), or because these are areas that are a particular priority for me.

Perhaps this is about my inexperience, but I think it's also about who is calling the shots, and I don't think it's us. The mental health system is not fundamentally ours, and so we are always participating in it from a position of exteriority. In this sense, I have a great deal of respect for approaches like the Hearing Voices network, which start with their own priorities, and then offering training – *on their own terms* – to the mental health system.

Instead, my teaching opportunities have come about indirectly from the Deakin workshops (see p.5) and more directly through my connections with two wonderful mentors – Merinda Epstein (and her long-time collaborative work with Noel Renouf, a social work academic) and Cath Roper (whose position in the Centre for Psychiatric Nursing at the University of Melbourne was established through the work of Merinda Epstein and Brenda Happell, a nursing academic). In my observation, many indirectly-related, flow-on opportunities have flowed from the very solid groundwork of these individuals – Merinda, Cath, Noel and Brenda (and probably others).

The role of flattery/ego/gratitude

Each semester, I am approached by people who are organising a course or a seminar, who have realised "we should have some consumer perspective in this" and then they wonder "who should we ask?" and because of the various networks I'm involved in, I get asked. For someone so new to this, I am constantly flattered by



this. *There is a part of me that is just so grateful to have an opportunity to share this thinking, to share my passion, to share my experiences, to have a voice ...*

But this is less-than-ideal. **This is tokenism** (despite most people being extremely well-meaning and likely to protest such an “accusation”). I am finding it increasingly problematic (and this reflects my increasing awareness, not a sense of things-out-there changing) that I am being invited to give a guest lecture *without the rest of the subject content changing* due to my presence in the curriculum. There are some subjects out there that have been conceived either exclusively by consumers, or in reflexive collaboration with consumers and non-consumers, but this is by no means the norm.

I’m also concerned about the lack of training in any pedagogical approaches. In fact, there have been no opportunities for this. I would like to become more savvy about teaching not just as “here are lots of ideas. Aren’t they great?” but as changing practices.

I’m also aware that I have had access to extensive educational opportunities and have many markers of privilege that tend to be associated with higher education. This has no doubt shaped the receptivity of educational environments to my teaching – I get mistaken *all the time* for a social worker! I’m curious as to how this shapes the teaching encounter. I often suspect that some students – consciously or unconsciously – differentiate between “people like Flick” and “real consumers” (or, as they occasionally say “our consumers”). I suspect many of them assume, from how I self-present, that I “am recovered” or “never really suffered anything serious” or “was never as messed up as the people who use our service” or whatever. I probably contribute to this image by being fiercely protective of “my story” and refusing to orient my teaching from this perspective, although I pepper in details and anecdotes. I sometimes feel compelled to include subtle indications that yes, I can be extremely messy, that I am definitely mad!! It’s so complex, because all of our experiences are valid and none of us should feel a need to prove anything. This is also all bound up with complex interconnections between class, naive assumptions about what “serious/real mental illness” means or looks like, and assumptions about the legibility of mental illness (ie. the idea that you can read it on our bodies). How often have people in other parts of my life tried to “read” my body to see how I’m going, not understanding how adept I am at visibly “doing OK” while being emotionally distressed not far from the surface.

I could go on, but I’ll just flag one more issue that hovers in my teaching, and that’s the notion of being “representative” of anything. It’s related to the idea of being “real” somehow. I can never represent anything or anyone, but nor are my experiences and knowledge confined to being “purely individual.” In my opinion, my experiences, teaching and what I share has been shaped as much by my world-view



and political/ spiritual/ intellectual orientations as by my diagnoses. I'm interested in how we contextualise what we say within a broader, heterogenous body of consumer thinking.

My Vision

I envisage (and this is a shared dream, not mine alone): consumer studies units flourishing at universities, like Indigenous Studies Units, where students with emotional distress/experiences of madness/being involuntarily “treated” or labelled/who identify as having a mental illness are supported through tertiary education, not viewed as having an unfortunate medical condition, but as a community.

As an inter-related project, our intellectual base deserves strengthening. I want to be part of fostering a mad studies program (or whatever we call it). I want our foundations to be stronger so that when we emerge to teach, we do so from a stronger collective base, not as isolated “brave” or “enlightened” (or “recovered”) consumers, but as part of a collective movement.





JOHARI WINDOW

Background

Developed by American psychologists Joseph Luft and Harry Ingham in 1955, later expanded by Luft.

What is it?

- A disclosure/feedback model of self awareness and an information processing tool
- Useful for assessing and improving relationships between individuals or groups/teams/organisations
- Clarifies power dynamics
- Four Johari window perspectives (or quadrants)

Use in social work practice in mental health

I have adapted this model to

- Help students enhance self awareness and reflexivity
- Assist students to enhance their understanding of consumers
- Explore the parameters of consumer/professional relationships
- Identify helpful and hindering practices
- Imagine alternate futures
- Focus on practical applications of ethical positions

Four windows/regions/perspectives

1. **SHARED OR OPEN/FREE AREA:** what is known by both consumers and professionals. Includes ethics/attitudes; feelings; behaviours; skills; consumer/carer hidden knowledge. Aim is to expand this area to enhance productive and affirming relationships by active listening; seeking feedback; improving the culture of the agency to make it welcoming and positive; awareness of potential conflicts and mistrust; sharing knowledge and skills; awareness of power.
2. **BLIND AREA:** what is known by professionals but unknown by consumers. Professional is the expert. This is not a productive or respectful space. Important of reflexivity, supervision, improving self awareness, awareness of how agency culture and practices inhibit more affirming ways of being professional.
3. **HIDDEN AREA:** What consumers know but keep hidden from professionals. Includes sensitivities, shame, fears, secrets. Why might this happen? How do consumers and professionals keep things hidden? How to encourage disclosure. How to improve respectful communication, better understanding and cooperation.



4. **UNKNOWN AREA:** feelings, abilities, weaknesses, fears and strengths/weaknesses unknown to both consumer and worker. Very much driven by hidden assumptions, attitudes, fears, shames and conditioned behaviours. Traumatic experiences of the system or life traumas which inhibit trust, curiosity. How to shrink this area: communication, awareness, mutual discovery/journeys, defining where want to be, soliciting feedback, openness to others.

-from Ann Tullgren



Consumer Perspective – MOCA (Management of Clinical Aggression) Training: Refresher Session Outline

[This training is accompanied by a brilliant powerpoint, exploring the various factors in clinical aggression]

***Speak with clinical trainer beforehand** – introduce yourself and check that they are OK to help with the whiteboard activity below and how you will present the common ground slide at the end. (see notes for clinician at end of this outline)

***Your cue slide on the PowerPoint presentation is:
Where does aggression come from?**

Step 1:

- a) Have participants pair up with the person next to them (preferably someone they don't know)
- b) Identify with partner one thing that makes them angry (not specifically work related)
- c) After 3-4 mins, bring group back together

Clinical trainer will write responses on whiteboard and will put them into columns where they fit under the headings of:

- Fear
- frustration and
- powerlessness.

Headings will not be known to participants at this stage

- d) At a 'move it along pace' ask participants to report to the group what their partner had to say
- e) Once responses have been recorded, ask group generally to identify emotions they connected with the experience
- f) Ask clinical trainer to 'sum up' what is recorded on whiteboard and to draw together the themes of fear, frustration and powerlessness (the RESPONDENT contributors to aggression)

Step 2: Discussion

Possible questions to tie back to goals (listed below):

- Do you see your responses as similar or different to the responses you see in consumers? How/why?
- From your experience, what can you share with the group around what has worked well for you when dealing with situations where consumers have been frightened, frustrated or felt powerless and have started to become angry?



- What do you think have been the main issues contributing to the above? (e.g. interpersonal relationships, attitudes, lack of information, boredom, choices/options, trust, grief, medication, empathy, early intervention, an apology)
- What might you take away from this session? (e.g. One thing that you can change when you get back to work)

Step 3: Summary

So, to sum up, we can see that all of us get angry and respond to that anger in different ways. The response often stems from frustration, fear or powerlessness. How those we are dealing with respond to us can make things either better or worse.

Common Ground:

This slide may appear. If not, in conjunction with the clinical trainer, present this slide that says:

- We are all coming from some common ground
 - We all have the right to be safe
 - We all want an aggression free environment
 - We all experience anger well and not so well
 - We all have triggers and react in a variety of ways
 - We all recognise that consumer morale and behaviour can be positively influenced by good staff morale and motivation
 - We all recognise that aggression management is about more than physical restraint and ‘take downs’
 - We all recognise that this is a very emotional topic

Notes for clinician for white board activity:

Participants will feedback the things that make their partner in discussion angry. As they feed back each item, place them on the whiteboard under the 3 headings of frustration, fear & powerlessness, **but do not let participants know these headings.** You will know which column is which & when the consumer presenter asks you to comment on what you have captured on the board, you can then divulge the 3 themes that have emerged. For example, participants may say that they get angry when they have to wait in queues & you may put this under the column of frustration or that they get angry when their boss does not follow up on something & you may think this goes under the column of powerlessness.

Aims of module:

At the end of the session participants will demonstrate an understanding that:

- Aggression is a response to a need and not always about pathology
- Every person can become aggressive to varying degrees in different circumstances
- What staff do may potentially help or hinder different situations
- Identifying practice may lead to change

If aims have not been met, ask questions to draw out responses to meet aims

-from Wanda Bennetts



The Understanding & Involvement Project (U&I): 1991 -2001⁹

What is/was the Understanding & Involvement (U&I) Project?

The U&I was a path breaking project that came out of a series of booklets put together by consumers from the Victorian Mental Illness Awareness Council (VMIAc) in the early 1990s. The particular trajectory that led to development of this special resource was publication of ‘Unlocking the System,’ (by Di Otto) then ‘Understanding, Anytime,’ (by Maggie McGuiness and Yoland Wadsworth) and then the huge commitment by many consumers into the “Understanding & Involvement (U&I)” project.

U&I was primarily a Participatory Action Research (PAR) Project that produced five volumes of work plus newsletters which were designed to inform and keep up to date the several hundred consumers and staff who were actively involved in the project. For me, it was one of those projects that seemed so comprehensive that I was confused. It was nothing like any other research project I had ever been involved in. In the first years, particularly, no matter how much I learnt about spirals of change I still wanted an hypothesis, the collection of data, analysis and some sort of encouraging end (report?).

Now I have a renewed regard for this amazing project. I recommend the books to everyone. I think the VMIAc still has a few copies if you get in quick. It is with hindsight that I realise just how brilliant this project was. The collection of data is incredibly thorough, fundamentally consumer perspective in its origin, and absolutely comprehensive. At some points where I know I was confused I now go back to the texts to find we were collecting, experimenting, feeling out, enticing staff participation and, at times, being bloody obstinate because that is what the situation called for. Re-reading this material has been heartbreakingly inspiring – because it has not been utilised to its full and real potential; but also inspiring because they’re

⁹ **McGuiness, M and Wadsworth, Y.** (1991) ‘Understanding Anytime’ – a consumer evaluation of an acute psychiatric hospital, Victorian Mental illness Awareness Council, Melbourne, ISBN 0646059912

Epstein, M. And Wadsworth, Y. (1994) Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project’s Beginning...’, (Vol.1), Victorian Mental Illness Awareness Council, Melbourne ISBN 0646164902 (V.1)

Wadsworth, Y. And Epstein, M. (1994) Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project Unfolds...’, (Vol.2), Victorian Mental Illness Awareness Council, Melbourne ISBN 0646277707 (V.1)

Wadsworth, Y. And Epstein, M. (1994) Understanding and Involvement (U&I) –Consumer Evaluation of Acute Psychiatric Hospital Practice: A Project Concludes...’, (Vol.3), Victorian Mental Illness Awareness Council, Melbourne ISBN 0646277715 (V.1)

Wadsworth, Y. (2001) The Essential U&I – a one volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services, Vic Health, ISBN 0-9579990 03



treasures that can be retrieved that are as relevant today as they were a decade and more ago. The U&I material is being used for the education of clinicians around the world. It is regarded with enormous respect.

The political climate

The Understanding & Involvement project emerged from a completely localised, grounded, response from a consumer organisation's demand that 'something must be done to change acute services' and that this must be driven by consumers. At almost exactly the same time Brian Howe (Health Minister in the Keating Government) drove forward the First National Mental Health Strategy (which included consumer participation for the first time in this country at this level of policy) and the National Human Rights Commission published the damning National Inquiry into the Human Rights of People with Mental Illness (Burdekin Report). In Victoria, the politics collided in a way it had never before. The same messages from consumers were coming both from the top down and from the bottom up through projects such as the influential U&I. It ignited into action and the U&I project was a major player in this movement towards change.

Education of the Clinical Workforce

In many ways the U&I was always both a research project and a clinical education project. Unlike traditional research PAR research has a remit to delve into crannies and poke heads around the many corners of mental health practice. In its era every single interaction we had with clinicians was an example of education. We were pioneering the concept of consumers-as-insiders within institutions designed to 'treat' outsiders. Of course this was an education for all. If you look through the booklets you'll find many examples of educational praxis explored by the project. I recommend everyone read it. However I want to mention just two more discrete examples:

The Communication Snake

This method was originally used as a research technique in 'Understanding Anytime' 1991 p. 7. The concept involves the consumer/researcher or consumer/educator acting as a conduit between two groups where they are presently great misunderstandings. In the beginning we used the concept to bring the opinions of consumers about acute hospital experiences to clinicians. Always starting with consumers, we'd ask them what they would like to tell or query clinicians. We asked them to be as specific as possible. For example, "*why are seclusion rooms still used?*" We'd then take the consumer question to staff and get a response which may be something like, "*because sometimes people are a danger to themselves or others*" (for example) and we'd take this back to the consumers... this would go on, back and forward, till attitudes had shifted. Sometimes they had shifted enough for both groups to feel safe enough to talk together in the one room.



Later we used this same technique for overtly educational purposes. An example was the Vignetter dialogue (p.117 in The Essential U&I). This involved consumers creating a vignette which generally implicated staff communicating or behaving in ways that hurt. We wanted them to be subtle rather than dramatically bad. Clinicians were asked by consumer educator how they could change the way the story went by changing the actions of the clinicians. They were not allowed to suggest changes to the way the consumer/s in the vignette acted or responded. The staff's suggestions were taken back to the consumers who made further comment and, if necessary, this comment was taken back to the staff. The Communication Snake wondering back and forward between consumers and clinicians minimises confrontation and enabling consumers to be free from their assumed role of placating staff; and staff to be able to react if they needed before concentrating on finding a solution to issues consumers have identified as important.

The Collaborative Committee (From 'The Chocolate Cake factor'

http://www.takver.com/epstein/articles/chocolate_cake_factor.htm

In the U&I Project we first became interested in deep dialogue (see separate pieces on Deep Dialogue) through what came to be known at the Collaborative Committee. Our committee was different. In putting together the committee we wanted and needed around us and around the project we deliberately invited people who were vitally interested in consumer participation in service delivery. We did not select people because of their authority or position within the organisation and we did not select consumers who were necessarily representative of a constituency. We said, "we are doing this project, who would like to join us." Invariably what ended up happening was that we attracted both consumers and staff who had witnessed or experienced things within the culture of acute psychiatric hospital practice that needed to be changed. We described this method of attracting people as 'organic'. It grew out of the soil of the project.

Secondly, we knew that there would have to be equal numbers of consumers as there were professionals at each meeting. The consumer voice would, we knew, be reduced to tokenism if this was not prioritised.

Instead of taking minutes we taped and transcribed each meeting because we accepted that the meeting itself was a microcosm of what happened in the real life relationships that play themselves out in a psychiatric unit. The taping of the meetings slowed down the thinking and forced all members of the collaborative committee to think about their language, to talk about their relationships with one another and to reflect collaboratively on their practice. So rather than a Steering Committee or a traditional research committee which would take on a management role for the project we developed as safe a place as possible that would also be a crucible for the fundamental issues that determine acute psychiatric hospital life.



In this collaborative committee we had an opportunity to:

...discuss the kinds of topics which at present rarely happen. You know when a committee gets into a very rare discussion about fundamental values, philosophy, purpose, and 'what we're all here for'... and everyone says, "Gee we never have this kind of discussion, this is really good, why don't we do this more often?" And then the chairperson calls the meeting back by saying, "Well I'm afraid we have to get back to the real business of the meeting – the staff's leave provisions, the auditor's report, the productivity savings the funder wants, and the quarterly statistics.

Our meetings operated more as 'think tank'-type sessions about deep issues like:

- Stigma, dignity, respect and power,
- Ethics and 'real' consent,
- Consumer exclusion from the life of the hospital,
- What constituted personal experience of good practice,
- The pros and cons of psychiatric medicalisation,
- Relativist definitions of mental illness from the point of view of psychiatrists, police, policy makers, therapists, consumers etc.
- Fear and violence, and
- The impact of legislation

The taping and transcribing enabled this precious material to be used for later teaching.

The Understanding and Involvement Project (U&I):

Several highly successful projects grew out of the U&I project:

- *Do you mind? The Ultimate Exit Survey* (see page 35)
- *The Deep Dialogue Project* (see pages 31 & 47),
- *The Lemon Tree Learning Project* (see page 38) and
- *The Lemon Looning Board game* (see page 44).

U&I won two national awards.

- **1995:** THEMHS (The Mental Health Services Conference) *Partnership in Consumer Category Gold Award*
- **1999:** Australasian Evaluation Society *Caulley-Tulloch Prize for Innovation in Evaluation*

- *From Merinda Epstein*



DEEP DIALOGUE: PROJECT ONE

Introduction:

Two projects known as ‘Deep Dialogue’ grew out of the Understanding & Involvement (U&I) Project and the following Lemon Tree Lemon Project. The two projects were quite different but the underlying principle was shared. It is an underlying thread that was first described in the U&I through the development of the Collaborative Committee. Next the same thread appeared, again in the U&I with the ‘Three Sites for good practice in consumer/staff dialogue for change’:

- the site we all probably know the best –decision making sites that usually look like familiar meetings and behave bureaucratically and predictably. These are the sites Flick Grey has come to call, ‘Other People’s Committees’;
- consumer-only sites where we have the opportunity to unite, plan, strategise, organise, gain critical mass and prepare for times when we will be relatively powerless; and
- non-decision making site where ‘real’ discourse can occur and where time does not have to be wasted making decisions often handed down by others. This is the site out of which Deep Dialogue emerged following the real success of the Collaborative Committee.

The thread re-emerged in the concept of root learning so central to the Lemon Learning Project¹⁰.

Deep Dialogue Forums

We wanted to test the idea that we could develop a structure that would allow for the deep conversations to continue taking place between consumers and service providers. Importantly, we developed a set of rules around how deep dialogue forums would be conducted. This was not to structure it into rigidity, rather it was to test what we had learnt in the U&I about what would best enhance meaningful dialogue between consumers and clinicians.

The Deep Dialogue Forum Rules:

50% consumers and 50% staff	More consumers (to even up the power imbalance) if this was deemed to be necessary in the early stages
Consumer initiated and consumer perspective facilitated	This also may mean consumer-chaired or/and consumer organisation facilitated



Organically grown	Like the town planner who designs a town square in a place where no one ever gathers and then is dismayed about its lack of use by the community, forums that are artificially constructed won't work. Many of us have seen what happens when organisational 'planners' start contriving a group. The group does not cohere or share a purpose and runs out of steam quickly. Here, people choose to come because they are wanting to (both consumers and staff) – often because of the way they or those around them have been treated by mental health services or the way they have seen 'patients/clients' treated. This is not bias. The expression the U&I project used was 'divining for where the energy is' which is good practice for many things including longevity.
Agenda Free/single topic	Meetings commence with a single issue such as medicalisation (for example) or prejudice or fear. There is no pressure to get through several items on the agenda. Indeed, there is no agenda. These meetings are driven by passion for change, not agendas.
Decision-free environment	What a relief this was for most of us. In Deep Dialogue no decisions need to be made. Those discussions that had traditionally been cut short by an anxious chair were now welcome and honoured.
Prefiguring good practice	People are carefully and actively listened to and people speak until they feel heard. There can be silence, discomfort, repetition of stories and the putting of different points of view. People can change their positions and ideas. Everyone, clinicians and consumers, get practice truly listening with an open willingness to postpone 'observing', 'listening for pathology', 'diagnosing' or explaining or 'tolerating' using the tools of psychiatry. We all had to learn to live with our embarrassment if someone needed time to tell the group than was comfortable for some. It's like we were all practising what we want to see more often in clinical practice.
Chocolate cake factor	Meeting over lunch or tea and cake. Sharing food. De-clinicalise the encounter. Any prop that can be used to bring people together and moving us all away from our roles as 'clinicians' and 'patients'. For some reason homemade food



	did this task better.
Location	Accessible place for staff and an emotionally and historically safe place for consumers. This can be hard to find but those involved in the original U&I Project found it in and around the U&I offices in the hospital.
Continuity of membership where possible	Trust-enhancing. There was an endeavour to keep the group as cohesive as possible and this meant trying to get the same people there each session. It was hard because, predictably, every other conceivable competing priority seemed to get in the way.
Internal Privacy	What wisdom is generated or lessons learned are the business of those attending, and each takes away from the meeting what they learn themselves.

In Practice

We worked hard to maintain the momentum of the deep dialogue initiatives but this was difficult for a number of reasons:

- It was difficult to persuade clinicians and managers that these decision-free discussions were important.
- And even when we could attract the numbers the discussions were sometimes hard:
 - Consumers, needed to tell and sometimes retell stories of bad practice. For many grass roots' consumers, storytelling is a fundamental communication tool. People won't stop till they feel heard. For some until some sort of remedy action is in process.
 - Clinicians on the hand sometimes felt less comfortable with their own stories as they struggled with what we couldn't help thinking were archaic definitions of professionalism. There were a number who couldn't help trying to 'help us' (that was their job!) and found it impossible to listen in the very different sorts of ways the process required;
 - Clinicians had problems allowing themselves to 'just be' as human beings with feelings like the rest of us. This was scary for them because it could potentially rob them of the clinical identity that protected them;
 - It seemed to us that the more consumers needed to tell stories of bad practice the more clinicians needed to hear stories of good practice.
 - We were mindful of the fact that these self-chosen clinicians (good eggs) who found themselves in the position of hearing and re-hearing stories of bad practice by their colleagues. There were times during the deep dialogue



where practitioners felt a need to defend their professional group or where they felt unfairly treated because it was not '*their*' personal practice that had caused the offence.

The challenges for the whole group within a deep dialogue context were to;

- maintain a capacity to keep asking each other questions and to dig deeper below superficial explanations or existing understandings;
- maintain the ability to continue to not criticise each other **and also** to not avoid raising the difficult topics;
- sit with silences and give people time to get the courage to speak up;
- maintain a systems perspective – that is, an ability to see how social expectations operated to 'structure' patterns of action and practices in ways that could either be experienced as determining or, if aware of them, could be used as levers and pulleys to bring about change;
- maintain a reflective space where energy doesn't have to be immediately converted into political strategy.

The Good News

- The good news was that the seminars survived for over a year after the end of the U & I project.
- In the end we wrote:
*"The provision of a 'space' and the sustenance of a culture of non-judgemental, non-decision making dialogue – where the spirit of deeper collaboration and respect is maintained whilst traversing the revelation of pain – remains fragile, tentative but continuing."*¹¹

¹¹ Wadsworth Y and Epstein M. - Understanding and Involvement (U&I) Consumer Evaluation of Acute Psychiatric Hospital Practice "A Project Concludes...", Victorian Mental Illness Awareness Council, Melbourne 1996 p 15



Do you mind? ... THE ULTIMATE EXIT SURVEY - Survivors of Psychiatric Services Speak Out¹²

Do you mind? The Ultimate Exit Survey is one of several highly successful projects that grew out of the U&I project

From Collaborative Committee to consumer-only discursive think tank:

One of the many innovations in the U&I was the turning of what started life as a very ordinary Steering Committee into something that was extraordinary – the Collaborative Committee. This committee is described in more detail in the piece on the U&I. The Ultimate Exit Survey was the product of a group of consumers who had been involved with the Collaborative Committee as a mechanism to collect high quality, unique data in the U&I project and wanted to utilise the same mechanism to produce high quality unique teaching materials to be used by consumer educators.

The Consumer Consultants Group Inc.

20 consumers who were involved in various ways in bringing the extraordinarily comprehensive U&I Project together felt a need to come together as a group of experienced consumer educators and researchers. We were very keen to continue to make a difference to the way services operated, the atrocities we still witnessed and the problems and issues that continued to plague the system. We became incorporated as this would enable us certain privileges such as the ability to raise funds and gain government grants. This was a huge process in itself.

We had a lot to say

As was the case with the Collaborative Committee in the Understanding & Involvement Project we realised that every time we met we were running high on precious verbal exchanges. This was material that clinicians across the spectrum of services delivery agencies and communities needed to hear. It was wasted on us! We certainly didn't always agree and this was important for clinicians to learn about as well. Here was the richness of the consumer discourse with all its bumps and lumps and grounded earthiness.

The Purpose of the book:

"I believe that it (The Ultimate Exit Survey) must become an essential resource for mental health professionals, as well as for all pre-service students studying in the field. Those responsible for in-service training activities should make themselves familiar with this material..." (From the *Forward* by Merinda Epstein)

¹² *Do you mind?... The Ultimate Exit Survey: Survivors of psychiatry speak out*, The Consumer Consultants Group Inc., Melbourne, 1997 c/o Ross House ISBN 0646 31386 X



The Editor

After deciding these deep insights were worth capturing we approached Yoland Wadsworth and asked her about how we could put the project together to create a product we could use for educating staff. This was its primary purpose. The courageous (and I think correct) decision was made to edit the material with minimal editorial intrusion. This enabled essence of the conversation: the hesitations, the interruptions of each other, and the passion to come through the words. Some people find it a bit challenging to read but as a teaching text it is fabulous.

Forward

In the forward I spoke of four important themes. They were:

- **Consumer perspective.**

“Although the individual service users speaking in this book have robust and engaging debates around their experiences of and opinions about different aspects of so-called ‘care’, there is also no doubt that there is a thread of mutual understanding, support, empathy and trust which all comes from having experienced the oppression that accompanies being labelled as ‘mentally ill’ in our society.”

- **Debunking myths about us having ‘disability of mind/thinking’**

These discussions are extremely sophisticated, probing, testing of myths and taken for granted assumption that mythologies about ‘disabilities in capacity to think’ are exposed.

- **We are ‘whole’ people and no just dislocated walking symptoms and diagnoses**

For an audience of clinicians and/or student clinicians who are embroiled in the cesspit of service culture determined by ‘illness’, ‘triage’, ‘diagnosis’, ‘prognosis’ and treatment-centric interactions this book reminds them of the most important fact of all, “we are people just like you with all the spectrum of feelings, behaviours and happenings that everyone else in society experiences.”

- **We are not ‘other’ than wholly human**

In the discussion consumers have and exchanges they encounter there is no way that those we wish to educate could ever imagine us as less than wholly human. No consumer is ‘other’ than wholly human and every small contribution that can be made that underlies this point is important.

Conversations from lived experience

There are eleven chapters in the book. Each chapter has been edited beautifully to maintain the essence of a conversation between consumers. There is no editorial overlay and because of this it feels like the discussions are being had in real time with people agreeing a lot of the time, building on each other’s idea, sometimes



having that ‘ah! Ha! I’ve got it moments’ and not infrequently disagreeing quite strongly. Consumer perspective traverses the chapters. People talk from their lived experience. This does not mean they agree. It is really beneficial for undergraduate students and clinicians exposed to the difference between ‘perspective’ and ‘world views’. Even though this book is over ten years old it still does its work as a grounded teaching tool exceptionally well.

The Substantive Material

There are 11 chapters and each contains a discussion with the different voices named so it’s easy to watch the stream of different consumers’ thinking. It was also a break through, in its time, because most of the people were proudly prepared to use their names – unusual then and one of the most essential things we have achieved in terms of fighting ‘othering’ especially in a document intended to go to clinicians who might, at any time, be treating you again.

Chapters:

- Chapter 1: Stigma
- Chapter 2: Empowerment and self help
- Chapter 3: Interpersonal Communication
- Chapter 4: Gender
- Chapter 5: Complaints systems
- Chapter 6: Treatment Plans
- Chapter 7: Rehabilitation
- Chapter 8: Crisis Assessment Teams
- Chapter 9: Police Involvement
- Chapter 10: Discharge Planning
- Chapter 11: Medication

- *From Merinda Epstein*



Developing Effective Consumer Participation in Mental Health Services: The Lemon Tree Project (1997)¹³

National Mental Health Strategy Innovative Grants Funding 1995

The Victorian Mental Illness Council (VMIAC) applied for and was successful in winning two significant grants from the National Mental Health Strategy Innovative grants Program in 1995. These grants were to:

1. Research and document the most effective ways that consumers could participate in mental health services; and
2. Develop an effective consumer peer support program.

Both were highly successful. The first we called, *The Lemon Tree Learning Project* and the second was located in St Vincent's Place, Albert Park. It was called *Vincent's*.

The Lemon Tree Learning Project

The Lemon Tree Learning Project was all about the education of the mental health workforce. There are two significant parts of this project. Both are relevant to the educational aims. The definition of 'education' drawn in the Lemon Tree Learning Project took understanding of the role of consumer educators abruptly away from 'people who speak at other people' and 'trainers with expectations of instant educational gratification' to a much more sophisticated idea of what it truly means to be an educator. The two important aspects that will be described here do not adequately cover the breath of the endeavour but it is a start.

Concept One: The metaphor of the Lemon Tree

This metaphor was totally central to our thinking in relation to the education of clinicians. It had the following aspects that were significant:

1. The Lemon Tree in our concrete back yard at the then VMIAC HQ in Weston Street, Brunswick;
2. Our collective feelings and reactions to the humble lemon;
3. The tree and its constituent parts: The roots; the trunk; the branches; and the leaves

The Lemon Tree in our back yard

The asphalt back yard of the small house which the VMIAC then called home was barren except for the Lemon Tree. This tree produced lemons and was green and protected us from the sun. We saw it as symbolic of life and possibilities for consumer power in institutional spaces.

¹³ Epstein, M and Shaw, J. (1997) *Developing effective consumer participation in mental health services: the report of the Lemon Tree Learning Project*. Victorian Mental Illness Awareness Council, Brunswick, Victoria.



Lemons: We had all sorts of associations with lemons. Nothing like a good brainstorm with consumers! Read the book. It'll tell all. However, some had to do with not protecting clinicians from sour educational experiences as the product, if they hang in there, could be sweet and wonderful. Others had to do with Lemmings – a bit farfetched but there you go...

The Tree Metaphor: This was of great significance to this project which had as its central goal of building change into institutions of psychiatry through consumer interventions – education defined broadly and focusing on the education of the institution through large and small scale intrusion of consumers into places we had never before been allowed to enter. Therefore it is unsurprising that we started with the roots.

Roots: Root work is about putting sufficient energy and time into nourishing the growth and development of an infrastructure for institutional change. It's deep, deep, slow and deliberate work with the institutions that maintain and control staff behaviours and attitudes – attitudes, values and behaviours we wished to change.

Root work is both the most important and the most difficult educational work we had to do. It was also the most difficult to describe, substantiate and, unsurprisingly, get funded. Convincing everyone of its fundamental purpose and promise is a major part of what we, as educators, must do. After several years of careful work we were convinced that without due respect for root work other educational interventions often do not achieve their potential.

Root education is not a discreet thing that can be neatly packaged then shared, sold, copied and branded. Rather, it is about the growth and nurturance of a new way for the organisation and staff to think about their practice. It necessitates organisations and practitioners reflecting on their practice **in collaboration with consumers**.

From the beginning, root work requires a critical mass of local consumers – not just a couple of tagged educators from outside (although we have our uses too). It is imperative, both ethically and in terms of changing the power dynamic, that local consumers need to be paid, and need to be paid respectfully. It will always include opportunities for **deep dialogue** (see pages 30 and 46) and culture carriers.

Learning will take place over a period of time – it will be slow.

Trunk: The trunk is the substance of educational interventions. At the time the Lemon Tree Report was being written there was nothing that could match the extraordinarily detailed research undertaken by the consumers working with the U&I Project. It did have a leaning towards acute units because of the nature of the funding but there is a logic towards focusing intervention education on the area that arguably has the capacity to do the most harm. See the U&I tenets below.



Branches: The branch work is about building onto and supplementing existing skills, knowledge and attitudes around consumer participation in all aspects of institutional change including ways and means of changing institutional attitudes and individual attitudes, values and behaviour of clinicians through consumer intervention.

Leaves: Unfortunately leaf work is the most common. Sometimes it takes the form of people telling their stories, sometimes not. But we mustn't fall into the trap of thinking that the use of story is confined to leaf work. Telling and retelling stories, particularly stories of bad practice and bad outcomes, is also fundamental to root work. Leaf work is about one offs! It includes one off talks. They are potentially useless ways to make change come true. They are discrete events that might be plucked by a service, waft around and fall to the ground in any number of unpredictable ways totally unconnected to the amount of emotion expressed at the time. Educationally leaves are the least effective.

Concept Two: the eleven important components of the Understanding & Involvement built-in Consumer Consultant Plan

The Lemon tree Learning Project chose to utilise the significant findings of the Understanding & Involvement (U&I) Project (see page 25). The comprehensiveness of the model and the thoroughness of the research undertaken by consumers working on the U&I project seemed sufficiently rigorous to form the content trunk of The Lemon Tree. Our role was to adapt this learning to an educational framework.

The U&I Model (The substantial trunk of the Lemon Tree)

It is important for as many consumer educators as possible have a chance to look at the U&I research. We can't do it justice here. However we can outline the very basics and simply encourage further study. One of the aims of the U&I Project was to explore how institutional practice can be improved through consumer led and staff collaborative commitment to changing the damaging institutions that control the behaviour, values, attitudes and conduct of services- service that are 'not good enough' for either consumers or staff.

However, consumers in developing the conclusions of the U&I argue that institutional malaise profoundly affects the '**done to**' (consumers) and that therefore they must be the educational leaders in the education of the '**doers**' (clinicians)¹⁴. The assumptions of the U&I model match the assumptions of the Lemon Tree. They

¹⁴ Wadsworth Y. The Essential U&I - a one-volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services, Victorian Health Promotion Foundation, Melbourne 2001, p.18

¹⁴ Culture carriers are staff or/and consumers working in services dedicated to carrying the 'message' of consumers on to as many other staff within the organisation as possible, It's a pretty hard job particularly if the carrier has little status.



are securely based on building new ways of thinking into the institutional assumptions that breed and support practice – both good and bad.

The 12 ‘musts’ from the U&I project. Consumers who worked for three years (and a bit) developed a comprehensive and really useful model which outlined the essential needs, including educational needs, of any institution introducing paid consumer staff. The U&I consumer team called these brand new positions staff-consumer consultants. The hyphenation of the staff was to indicate that consumer work was not to do jobs that belonged to paid clinicians but rather to indicate to clinicians work that the institution must now find staff to action. The Lemon Tree Learning Project liked the comprehensiveness of this model and we made it the substantive trunk of the learning tree. The 12 parts of the U&I model are listed below and can be found in more detail both in the Lemon Tree Learning Book and in The Essential U&I pp 189—198. Consumer activity must be:

1. **Built in to the services and never an add-on.** It must be part of the quality assurance/quality improvement framework;
2. **It must never be seen as just eliciting local consumer feedback** and we shouldn't be enticed by fancy looking tick-the-box feedback forms or the promise of greater clout with professionally prepared feedback material. Rather, it has to be about a conversation between consumers using the services and other consumers – two-way dialogue will teach us heaps more than ticking the box. This also applies to conversations between staff and consumers who have used services provided it is safe.
3. **Consumer led education for staff must be comprehensive and systemic.** These must never be leaves. At the very least it needs to be built into the educational calendar for the service;
4. **Consumer participation for change in psychiatric institutions must be robust and ‘built in’;**
5. **To achieve institutional culture shift consumers must be supported to become and help enable supportive staff to become the carriers of a new consumer-respecting culture.** The support for this is crucial because it's a very difficult task and needs the development of a critical mass of like-minded consumers and staff;
6. **Multiple consumer feedback methods and ‘mechanisms’.** Nothing will change with one off lectures from consumers or one exit survey, or...; There are dozens of different ways the institution can be told about our experiences – ways for people who want their feedback to be confidential AND for those who want their names emblazoned. All have a right to speak back in the way that works best for them;



7. **Three ‘sites’:** These sites are essential: consumer-only places where we work out strategies, get confident and make our own decisions, decision-making sites (like meetings and the like) and, crucially, non-decision-making consumer/staff sites such as opportunities for deep dialogue.
8. **Centred on the acute unit and other high risk settings:** Partially this was because of the nature of funding for this project but much more importantly this is because the Acute Unit, Accident & Emergency Departments and other key spots are the most likely sites for harm to be experienced.
9. **Consumers as staff:** after three years of careful, methodical research by consumers we realised that if we weren’t actually there to drive clinicians to fulfil their new commitment to ‘listening to consumers in different ways’, to finding every possible way to get feedback and, not just feedback, but real conversations with consumers about what is going wrong’ etc, nothing would happen. Consumers needed to be on board within the organisation to drive change. However, without the other 10 support structures we knew this central but difficult task of consumers employed as the carriers of a new culture would be risky and hard.
10. **Consumers support resources infrastructure:** Consumers working with the U&I project needed a raft of supports built in from day one. Consumers participating in discussion and those on acute units who were able to have conversations-for-change also needed a bundle of support structures. These are explored more in the U&I and the Lemon Tree texts but there was no way we would have recommended employing consumer consultants without very specific, built-in supports including supervision from consumer leaders (or other trusted supporters) from Day1.
11. **Consumer driven and staff collaborative:** This was an important aspect of this highly developed package. The U&I Project was about staff changing their views, values, attitude so that:
 - priority might start to be given to those aspects of practice that consumers identify,
 - getting feedback and having constructed conversations about service, safety, ‘care’, ‘treatment’ etc gained institutional status;
 - and so on;In this model these exchanges are not about ‘sharing opinions’, ‘educating consumers’, ‘working out our differences (glibly said without taking on board huge differences in power). Rather they are driven by consumers (who are not paid to be patients in hospitals) supported by consumer consultants. But staff are expected to play their part collaboratively. They are expected to listen to consumers in new ways and with respect, ask questions, clarify missed



meanings, ask consumers for examples of good practice and any number of ways they need to operate to take a large chunk of the load for changing what can be a damaging mental health system.

12. **At all levels of all relevant organisations:** Consumers know about powerlessness. Consumer researchers know what it feels like to be talking what makes perfect sense to us but which seems totally incomprehensible to those who have the real power to make the important decisions, stall, or play bureaucratic games. The U&I model sort to make sure consumers held positions throughout all levels in organisations and within the overriding bureaucracy to enable consumer-sense to be spread especially into the most senior places.

-From Merinda Epstein



The Lemon Looning Board Game¹⁵ *an education tool that's worth learning how to use*

History

The Lemon Looning Board Game came out of a strong history of education, research and the production of fine quality resources by consumers at the Victorian Mental Illness Awareness Council (peak body for consumers in Victoria) from the late 1980 through the 1990s.

As part of the Lemon Tree Learning Project, we created the Lemon Looning Board Game. The idea for the game as a unique, interactive learning tool originally came from Sara Clarke and the inspiration to push us through to the completion of the design and then extraordinary negotiations to get the game produced by an up market firm for minimal cost was the work of Julie Shaw.

What is the game?

The best way to find out what the game looks like is to go and examine one. It's a board game. Around the outside are squares that represent 'consumers in the community'. There are three inside places; one is a public hospital, one is a private hospital and the third is a magic place that represents psychosis. The idea (ostensibly) is to make your way around the board till you get to 'the path to wellbeing' but as you can read below all is not what it seems...

The relevance of the game;

It is now over ten years since the Lemon Looking game was produced and yet the content is still totally relevant. This is both shocking – in terms of the lack of progress we have made in service culture and practice. Consumer players are still able to tell pertinent stories inspired by the squares on the board. It is also encouraging because it means that whilst copies of the board game still exist we can return to providing proper training for consumers which will enable the games that are left to be utilised in the way they were intended and, once again, provide unique, difficult, frustrating, powerful training for clinicians. It's important not to lose this opportunity.

Ways not to use the Lemon Looning Board Game – you'll be disappointed and the game won't live up to its really effective best:

1. The board game cannot be used without training by people who are trained/experienced to provide this training. At the moment in Victoria this is Wanda Bennetts & Merinda Epstein.
2. The first and most golden rule is that these games are to be in the hands of consumers. They are designed for the exclusive use of consumer educators.

¹⁵ The Lemon Looning Board Games are available from the VMIAC VMIAC, Building 1, 22 Aintree Street, Brunswick East, 3057, Victoria, Australia. Phone: (03) 9380 3900 | Fax: (03) 9388 1445 | © vmiac.org.au



3. The board game is **not** designed for, and could be dangerous if used in, any of the following situations.

- put in acute units for occupational therapy;
- staff using it with consumers in acute services or in Psychiatric Disability Recovery Services (PDRS);
- one game on its own played after dinner or as any form of entertainment;
- staff playing it together;
- carers using it in any way whatsoever;
- untrained single consumers using it with a table full of staff;

How the Lemon Looning Game is magic

The Board Game is not what it might seem. This is one of the reasons it works. It also means that it is essential to have training. It is also VITAL to read the instructions. Some aspects of the game are self-evident but some parts are not. The game works on two levels:

- The game provides an opportunity for less confident and less experienced consumers to offer participating staff the chance to quietly and non-defensively listen to them about their experiences. The different squares on the board offer prompts for storytelling. Stories can provide very powerful learning opportunities. See Our Consumer Place's publication – "Speaking Our Minds: A guide to how we use our stories" (www.ourconsumerplace.com.au/resources)
- On a totally different level, the board game mimics the lives of many consumers and many clinicians – particularly the very competitive variety. This capacity of the board game must be managed with authority and hence the need for training. There are several aspects to this:
 - i. Very rarely does anyone get to the end of the game. There is usually no winner. This is totally intentional and is designed to emulate many people's experience of 'mental illness' and 'service delivery' – the frustration around the board is palpable often and we are so tempted to jump in and relieve the clinicians who want so much to win but the purpose is for them to sit with this frustration for some time at least.
 - ii. In a related way, it is possible to get stuck somewhere like the High Dependency Unit – something familiar to consumers but not clinicians.
 - iii. Consumers who are running the game are taught to quietly put their hand over the dice between turns so they can control how long stories can keep on being told. Again, many clinicians, especially those who have been trained into having highly competitive roles, just want to keep playing so they can win. They don't want to listen to people's stories but they have to because they can't get the dice.



Power

One of the most important things that happens when this tool is used properly is that we have deliberately built in ways to increase the power of consumers and simultaneously reduce the power of clinicians. This has been done very deliberately. Much more is learnt, always, if the power differential is more equal. Some of the precautions we have taken to build up the power of consumers include;

- All consumers must be paid in accord with their considerable expertise as consumers:
 - this can make it quite expensive training in the eyes of managers (if compared to other consumer training) but still heaps cheaper than most outside consultants;
 - Proper remuneration increases people's feeling of authority and ownership of the activity;
 - Consumers have to be trained first before they can lead the game with clinicians.
- When training clinicians using this tool there must be equal number of clinicians and consumers (usually 3 each) at each table (with one game). This gives us the elusive critical mass needed to reduce power initiatives.
- Because of the training consumers working with the game are familiar with it and staff are not. Individual consumers have practiced particular stories and know which squares on the board they want to speak to.
- Consumers control the dice and the stop watch.
- Consumers run the pre-game activities/stories/ice breakers.
- Consumers run the post game interactive activities.

Importantly, it is the consumer educators' role to pull the whole thing together at the end of the session.

This is difficult and the pre-training is essential so that we know people feel competent and confident if complaints do come. It takes training and skill to hold these precious moments of dissonance. The educator has to be ready for this and have practiced responses. These kinds of frustrations were built in to elicit exactly these responses from staff and educators need to be able to twist the energy around and ask: "why are you reacting like this do you think?" "What is it in your training that may be influencing your reaction?" And so on.

-From Merinda Epstein



The Second Deep Dialogue Project

Consumer-Staff Collaborative Groups: A Strategy for Enhancing Workplace Culture in Pursuit of Quality Outcomes

From The Lemon Tree

Unlike the first Deep Dialogue Process which organically emerged from the Understanding & Involvement Project, the Second Deep Dialogue Project started when a psychologist approached the Lemon Tree Learning Project with some ideas that he was interested to explore. This led to an interesting project which was a partnership between the Victorian Mental Illness Awareness Council (VMIAC) and North West Mental Health Service. It achieved a lot, was educational for everyone and also shone a light on some interesting mistakes made by the two organisers – of whom I was one.

What we did

The concept came in essence from its predecessor in the U&I Project but with some differences in energy, structure, control, expectations, time and organisation. In essence the project;

- Brought together four very experienced consumer advocates with four staff, (self-chosen) from one rehab unit in a psychiatric hospital.
- The emphasis of discussions was consumer experience in mental health services. It was a reciprocal exchange, not in terms of a straightforward exchange of views, but in the mutual exploration of what it means to be a consumer of mental health services.
- Consumers were encouraged to understand their role as a educative one.
- The discussions were facilitated.
- The exercise was conducted over ten weeks.
- The facilitators met with each group separately for two consecutive weekly sessions before the joint work started.
- The two groups then came together once a week for six weeks for one hour and fifteen minutes of discussion.
- Participants (except the facilitators) completed questionnaires designed to assess attitudes and beliefs around staff consumer relationships. These questionnaires were filled in on three separate occasions: before the discussions took place, at the conclusion of the series of discussions, and six months after the event.
- Participants would keep diaries of their experience of the dialogue



- The process was organised and assisted by the psychologist from the health service and the Victorian Mental Illness Awareness Council.
- Discussions were confidential to the group.
- The group met in the boardroom of the Mental Health Research Institute, Parkville.
- The second stage was to send these clinicians back into the workplace as culture carriers – a term used in the Understanding and Involvement (U&I) project to describe the skilled art of bringing in new ways of thinking and doing by practicing them in front of and with peers as well as taking more structured opportunities to introduce staff to new ideas. All four staff participants would be supported by consumers during a three-month trial back in the unit.
- There would be an evaluation undertaken by consumers after four months.

Successes:

1. A cursory look at the evaluation of this project shows that all four staff involved did return to their unit with a very strong desire to influence their colleagues. They reported that all coming from the same unit was imperative for encouragement and they reported having organised a special staff meeting to raise the issues and a survey to garner what support they had. The significance of this is great if you consider that these were not senior staff.
2. One staff member commented that: "*We want to review issues around seclusion, debriefing, relationships and power.*"
3. However as the money dried up to continue consumer support of the four culture carrier staff and after the evaluation was complete, this activity probably slowed down and the eventually ceased. On the other hand we expect that the four people actually involved in the sessions were probably personally changed forever.
4. "Evidence from the interviews strongly suggests that this process cannot be presented in a one-day workshop format. The key attributes of the process, communication and reflection take time. Staff reported that the time between sessions gave them an invaluable opportunity to think about issues raised, and to make connections between these and workplace practice. To ensure optimal outcomes in quality improvement this format is essential." This conclusion is supported by the findings of the Lemon Tree Learning Project, which reported that *there is no evidence of one-day sessions leading to ongoing change in staff practice or culture.*



The following factors were seen as critical to the success of the project by those consulted during the evaluation.

- The program was developed in collaboration between service and consumer organisations.
- The project was managed by an organically formed Steering Group made of staff, consumers and interested others.
- Implementation of the project in workplaces where there was pre-existing awareness of consumer issues, structures for consumer consultation, and support from management.
- Joint facilitation by two experienced practitioners.
- A planned program of sessions held weekly for at least ten weeks.
- Staff who were not forced to be involved.
- Involvement in the group of a number of staff from the same workplace.
- Employing consumer participants familiar with consumer systemic advocacy and issues in mental health services, but who were neither 'representatives' nor current or recent ex-patients of the area service
- Payment of all consumer participants for their work and for their travel.
- A location was chosen for the pilot away from the workplace and comfortable for participants, but still needing to be accessible to staff who might be on duty.

The mistakes we can all make ...

There were some real issues that came out of the dialogue sessions and some important criticisms about the way we set them up and serviced them. It illustrated, in part, problems that can occur when there is co-facilitation with clinicians and/or services when the consumer co-facilitator has significantly less power. As a co-facilitator I let things go that I should not have. Nearly all led to problems and I was cross with myself afterwards. If I had been a group it would have helped. A couple of examples of this were:

1. The facilitators were psychotherapists. Consumers understandably argued that they were not neutral; they were clinicians and they argued that therefore there were six clinicians in the room and only four consumers. The therapists were shocked by this candour.
2. We bought flowers to the facilitators at the end of the sessions. The consumers, knowing that the facilitators were paid felt this was prejudicial and discriminatory. Everyone should have had flowers especially since the pay to consumers got stuffed up. This wasn't about flowers, it was about the meaning behind the exclusivity of the gesture.



3. I was never introduced to the two facilitators (and, never asked to be – to be fair). I had an intuitive concern about the psychologists' determination to have psychotherapists involved. All this was a mistake because I was telling consumers one thing and the psychotherapists were being instructed quite differently.

Tidbits

- Much to their surprise (and maybe ours) the group that probably ended up learning the most was the two psychotherapists!
- The huge, magnificent, table in the Boardroom worried the staff much more than it put off the consumers.
- Consumers found themselves looking after staff during the sessions.
- This Deep Dialogue Project won the Gold Award at The Mental Health Services Conference in the Partnership Category in 1999
- One of the psychotherapists was sufficiently intrigued to write a paper on the process to present to a conference of psychotherapists. I saw a draft. It was reflective and striving to understand 'consumer stuff' - not there yet though.

Some Quotes;

Here is a small selection of quotes for the evaluation. They say more than any analysis.

This is not about reciprocity between staff and consumers – not here to learn from each other: Consumers stated that they thought they were there to inform staff about consumer experience and did not see how this could usefully be reciprocated. One stated: "*For us to learn how to be better patients isn't going to help the system.*"

Consumers taking care of staff: One of the facilitators commented that "*I thought the consumers were very gentle, though they were sharp with their tongues it is true ... given what they could have gone to town about, they were really restrained.*" Several consumers reported that they attenuated what they said to make it easier for the staff.

Psychotherapists: The facilitators in the Pilot were introduced to participants as "psychotherapists." Some consumers and staff expressed ambivalence about having 'therapists' involved in the project. One person commented that one of the facilitators got: "...*so far up my nose I thought [they] were dancing on my brain.*" They added: "*The psychotherapeutic gobbley-gook just annoys me so much.*"



REAL KNOWLEDGE



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DRAFT of a HELPSHEET from Our Consumer Place

TEACHING IN PARTNERSHIP WITH A CLINICIAN/ACADEMIC *an example from the field*

To live is to choose. But to choose well, you must know who you are and what you stand for, where you want to go and why you want to get there.” Kofi Annan

Introduction

This piece is based on an example where a consumer and a social work academic worked together to design a course and teach it successfully together over six years.

The word ‘partnerships’: is wheeled out frequently to describe situations where the fundamental power differential is so great that any meaningful ‘partnership’ is impossible. Many consumers recognise partnerships that aren’t partnerships and resent the term. Others are so grateful to be included as ‘a partner’ that they either accept the fact that there is no real partnership involved or look towards partnerships – real partnerships – developing through time.

What made this partnership work?

Regard: Both the consumer and the academic had high regard for each other and their work;

Power: Both acknowledged the power differential -- the academic had responsibility if the course went pear shaped. There was no pretending that both educators were equal in the eyes of the students either. After all, it remained the academic’s responsibility to mark papers and awards grades. For undergraduate students this is paramount.

Sharing power: Recognising the University as an artificial environment often governed by grades rather than true insight, both the consumer educator and the clinical educator were constantly communicating about how power was being shared and what needed to be done constantly to convince the students that the consumer point of view matters.

Loved Teaching: Both loved teaching and often the love of teaching was a much more important force than any content.

Teaching broadly and sharing responsibility: Both the consumer and the clinician were involved in every issue in the curriculum – sometimes leading and sometimes joining in from the side with the consumer leading slightly more sessions than the academic.



The pay was good and the academic was spot on with making sure money came through the cumbersome University payment process with the greatest speed.

Enjoyed bouncing off each other: The clinician and the consumer enjoyed bouncing off each other. In this way the third and fourth year social work students could see the different discourses actually being played out in front of them. Some were shocked at first but this was a fundamental reason why the partnership worked.

Taken for granted assumptions subtly questioned: Lots of taken-for-granted aspects of undergraduate and immediate post-graduate academic courses were put on their heads. For example:

- The consumer session came first instead of last. Consumers ran their own small groups and consumers new to doing this sort of work were encouraged to take part;
- The sessions on diagnosis started with ‘Borderline Personality Disorder’/‘Complex Post Traumatic Stress Disorder’ and ended with ‘psychosis’ and ‘schizophrenia’.

The Consumer Educator was a generalist and seen as a generalist: The consumer educator did not just take the sessions on ‘consumer participation’; she also took the session on ‘Mental Health and The Law’, ‘Stigma, Discrimination, Prejudice and Oppression’; and so on. She chimed in on many more.

Conditions for success:

- There needs to be some electricity between the two key players. This comes from real regard, trust, shared values and an interest in new ideas.
- Honest evaluation was attempted especially when things didn’t go according to plan;
- Commitment over several years perfecting the technique.
- Shared concern for the welfare of students who ‘come out’ as having a mental illness in front of their peers. Shared courses, by their very nature, encourage this and it is not always a ‘safe’ thing to do.
- Shared sense of humour and fun.
- Interest in the content and a shared determination to ‘sell’ mental health as a place of opportunity, challenge and rewards for undergraduates coming to the end of their social work course.



DRAFT of a HELPSHEET from Our Consumer Place

INTERESTED IN CONSUMER PERSPECTIVE TEACHING? *INCREASING OPPORTUNITIES FOR CONSUMER PERSPECTIVE IN ACADEMIA*

I cannot be a teacher without exposing who I am. Paulo Freire

Introduction

There is still work to be done to ensure that all students entering the mental health field have access to continuous consumer perspective teaching across their education.

What makes teaching consumer perspective?

In order to answer this it is useful to go to the Our Consumer Place website – www.ourconsumerplace.com.au – and look at the definitions we are using to describe consumer perspective. It is more than just having an experience of being diagnosed with a ‘mental illness’. It is more about seeing what is happening in mental health through a prism that is our own practical experience. It is possible to have a diagnosis of ‘mental illness’ and even to have experienced many deprivations and still not have a ‘consumer perspective’. To some extent it is a choice. For many, we long ago lost the capacity to make choices about it as the experience of the ‘mental illness’ and the consequent behavior of communities and clinicians embroiled our lives within the consumer identity.

Leadership

Governments, educational bodies, and professional disciplines need to display leadership in requiring that consumer perspective teaching is mandatory for the development of a contemporary mental health workforce. Consumers who are already involved in teaching are well placed to develop their contacts within institutions, and advocate for additional opportunities to embed consumer perspective in preparing mental health practitioners.

Consumer Academic: One form of involvement is to have a consumer on staff in a tertiary setting. The term ‘consumer academic’ describes a consumer position within a tertiary setting. When a consumer is on staff, there are opportunities to be involved in more substantial and ongoing ways:

- a consumer academic is involved in regular teaching, rather than one off sessions;
- S/he may team teach alongside another academic or mental health practitioner;
- S/he may develop and teach an entire subject, setting and assessing student assignments, setting required readings and administering the subject.



Teaching a whole subject allows a significant amount of content to be covered, places authority with the consumer teacher, and exposes students to regular rather than one off consumer perspective.

- But there is also power in numbers. With several consumers present as teachers, more depth and breadth of experience can be covered, and any perceptions of being the solo ‘non clinical’ or ‘lay’ perspective can be mitigated.
- There is more opportunity for creative learning and altered dynamics in a classroom when there is more than one consumer teacher.

Consumer Perspective is not just about teaching, it also can influence:

- course structure, delivery and review;
- the expectations of students’ workplace competencies, through involvement in curriculum committees. Opportunities for consumer perspective to influence other teachers and practitioners occur because the consumer academic is readily available. This provides a path to bring consumer perspective writing out of the ‘grey’ domain and into ‘peer reviewed articles.’

In order to understand the importance of this the terms need explaining. ‘Grey Literature’ is the term that is used to describe anything written (in this context, by consumers) which is invaluable but never gets formally published. ‘Grey material’ is sometimes missed by traditional search engines. ‘Peer Reviewed Articles’ are right at the other end of the continuum. These are academic pieces that have to go through very strict protocols and review by other academics. It is very hard to get anything on consumer issues into this ‘elite club’. However, having consumers in academic positions increases our chances, which enables us to reach an important and powerful audience.

Questions you can ask:

Next time you are invited to provide consumer perspective teaching, consider asking questions like these: Can I develop a session, set some tasks and come back in a few weeks for follow up? Can I set a required reading for the students? Can I set an assessment task for the students and mark it? Have you thought of using a consumer panel to provide a broader range of views? Do you have consumers on your curriculum committees? Is there significant consumer content in the other professional courses at this institution? How might we address this together? Have you considered employing consumer staff members? How else might we increase the amount of consumer content within undergraduate and postgraduate courses at this institution?



SUGGESTIONS FOR NEW STAFF

How should you act towards a Consumer of Mental health Services?

There is an easy answer - like you act towards anyone, like you would like to be treated yourself

Specifically

- Listen
 - Don't be impolite,
 - Don't 'humour' people,
 - Answer appropriate questions honestly,
 - Politely refuse to answer questions which seem more personal than you are comfortable with
 - Assume what people say has meaning until the opposite is proven,
 - Don't make promises you don't plan to keep.
 - Realise that being different is not the same as being inferior,
 - Realise there are other reasons for people's emotions and even suspicion of you than 'illness'
 - Remember that most consumers really like talking to a new person , and don't expect you to be 'experts' already
 - Remember that most of the people who use services that you meet will know a lot more about those services than you do, so treat what they say with respect
 - And finally, try to see things from the consumer's viewpoint – it can be quite educational and 'therapeutic' for both of you!
-

By a consumer of Mental Health Services

-from Bill Moon



DRAFT of a HELPSHEET from Our Consumer Place

HEY YOU! YEAH YOU! THE NEW WORKER READY TO CHANGE THE WORLD AND FIX SOME LIVES, WELCOME!

"We hope your stay as a psych worker is a long and productive one"

Here are some hints that may help you do the most good and the least damage along the way:

1. A diagnosis tells you nothing about the person, it tells you their diagnosis, which, if correct, can act as a map to best helping them. But too often it is used as a cage to trap people in. My diagnosis doesn't warn you that I think I am incredibly funny and know I am politically unsound. It tells you nothing of my aspirations or achievements, physical health, food preferences or about how I pick my toenails when nobody is looking. They are just a map on one page of the book of us and they may very well be wrong.
2. You may well be seeing us at the very worst time of our lives, remember that always.
3. "Nothing about us without us!" – include us in our own care as much as possible in whatever ways we are best able to communicate.
4. Don't be afraid of connection, it can be the most healing power of all. Knowing you also love gardening or cooking or lego and discussing those things can help us feel much less estranged from the world, when the world seems to be telling us all is wrong and weird with us.
5. Psych services can be really scary places full of scary and scared people. Never assume that just because we are one of them that we are comfortable in the situation. Would you be?
6. We have lives when we are not in your care – stuff outside still needs to be taken care of: bills need to be paid, the cat needs to be fed and the kids need their noses wiped. Telling us to not worry about that stuff doesn't make these things happen. Even if you can't fix anything, letting us talk about the frustration and fear and helping us to work that stuff out can be as healing as any medication regime. Hospitalization is a huge, stressful event in any life, let alone adding in an illness that may be changing your thoughts and attitudes, emotions and reactions
7. Accept that "the file" is written by flawed human beings who may have gotten things wrong. Think about how often in your life you have been misinterpreted. Imagine if you had no idea at the time, it was just written down and all that follows will be based on it. It sucks! If something doesn't seem right, come to us



and ask. Make sure you write down what we think is important for people to know, even if you don't see the relevance. Knowing that we are being heard is really important. You don't have to agree with it to record it.

8. Just because we are judged to be nuts/mad/sanity impaired/loony toons/people who/one in five doesn't mean that we automatically want to look and live like what you consider "normal." That may never work for us, we may not want it and even if it is possible the costs may be astronomical. Work with us to find out what "well" looks and feels like for us – that should be our collective aim.
9. I'm sorry to break the news but no matter how wonderful you are, no matter how politically sound you are, no matter your intentions... if you can hold us against our will, medicate us, write things in a file we can't read and make decisions about our lives we will **never** have an equal partnership, ever. It can't happen. We can be partners, we can collaborate, but it takes extra effort from you to recognise that no matter how touchy feely and wonderful you are, you still hold power. If you hate that idea, get out now. If you like it a lot, please get out now. Just don't pretend otherwise, we know it is bullshit.
10. Look after you, we need good workers. Maximise your leisure time, laugh at the funny stuff and don't pet the sweaty stuff. Always remember the divide isn't that big, we have more in common as human beings than any differences so-called illnesses provide. You can have bad days, please try to let us know it isn't our fault if it isn't. Remember we can have bad days too. Good luck!

This HELPSHEET was written by Sara Clarke for Our Consumer Place



DRAFT of a HELPSHEET from Our Consumer Place

WALK A MILE IN MY SHOES, PLEASE

Five important messages to give friends, family and the community about language

"If you talk to a man in a language he understands, that goes to his head. If you talk to him in his own language that goes to his heart." Nelson Mandela

Introduction:

Language is central to consumers' fight to become a genuine part of our social world (inclusion). This pamphlet is designed to help people teach their friends, family and the community about 'mental illness' from a consumer perspective.

- 1. 'People Who' language:** When people say '*the mentally ill*' or '*the schizophrenic*' for example, the person disappears and all there is left is a shell filled with deficits – the illness, the category, the stereotype. When we say; '*a person who hears voices*' or '*a person who sometimes gets very frightened*' we bring the person into full view and we also directly stipulate that the experience of the 'illness' is only something that happens sometimes. **It is NOT that person's identity.** This is a vital message. It is central to the consumer perspective and if there is only one message we want to repeat to the community over and over again it is this one.
- 2. Person First language:** This is about putting the word person before any, and all, descriptors. For example, it is not damaging for most of us to be described as a person who is diagnosed with a 'mental illness' or a 'psychiatric disability'. However, it is offensive for many of us when we are described as 'beds' or 'cases' for example. When services talk about case management or a case study, the person gets reduced to an object and once we're understood linguistically as an 'object' the opportunity for abuse increases.
- 3. The use of the word 'not':** There are many words that are used by the community to describe people diagnosed with 'mental illness' which are prejudicial. These include; dangerous, compulsive and violent. Some anti-stigma campaigns have worked hard to counter these erroneous community beliefs. They have done this by raising the issue frequently and using the word 'not' as a prefix. For example, 'people with mental illness are **not** dangerous'. The constant use of the prejudicial statement leads to people associating mental illness and dangerousness, despite the "not" thus reinforces the original flawed concepts. It effectively plants the negative in the listener's ear. Once planted the message becomes the opposite of what was intended.



- 4. Describing observations with simple lay language rather than embellishing them with judgments:** From a consumer perspective it is often better to use simple words like 'has' and 'had' rather than emotive language such as 'suffer', 'burden', 'afflicted', 'struggling', 'victims'. For example; 'he has depression' is very different from 'he is a victim of depressive episodes', 'he is afflicted with depression' or 'he struggles with the burden of depression'.
- 5. Self determination/integration:** Some consumers are starting to criticise both terms: 'rehabilitation' and 'recovery'. Instead they are turning to ideas like self-determination and transformation. That is, they are looking at the 'illness' experience as giving them an opportunity to rediscover themselves. They are designing a new self and new style. They are intentionally reforming themselves into something different.
- 6. Service for?** When we study the material produced by mental health services we commonly read about the services providing services **for** their clients or patients. This frames us as passive recipients. We see this language (and hear this language spoken) at the same time as attempts are being made to create services where patients and clients are encouraged to make decisions and do things for themselves.
- 7. Caring for v caring about** Many of us, especially when we are adults in a relationship with our parents, baulk at the idea that we are still being 'cared for'. We believe there must be less judgmental language. 'Care for' implies the roles are rigidly defined – the 'carer' in relationship to the 'cared for'. This language also implies that this is **the** relationship between the two people, non-wavering and indefinite.

Much of what is written in this pamphlet has been adapted from an article written by Harold Maio and Sylvia Caras. In this article there are other examples of language that consumers would like the community to think about.

Words Matter: <http://www.peoplewho.org/documents/wordsmatter.htm>



Biographical context for some consumer educators (and other educators working alongside consumer educators):

Sandy Watson (B.A; M.P.S) is an independent consumer educator with almost 20 years experience. In this time she has presented workshops to consumers and carers, homeless people, mental health workers, barristers, sheriffs, court clerks and magistrates' assistants, electorate officers, police, TAFE workers, law students and psychiatric registrars. She also appears in a number of educational DVDs, presenting aspects of her lived experience, for audiences such as general practitioners, police, employers, and community mental health workers. Sandy appeared as newsreader 'Sarah Tonin' in the witty Mental Health Coordinating Council (MHCC) DVD, *Breaking News*, for the Consumer Broadcasting Corporation (the CBC)! Sandy is innovative as a trainer, and between 2000 and 2006 produced several training resources and games to supplement her workshops with activities designed to help consumers expand their knowledge of rights, learn about committee terms, understand aspects of role strain and so on. Her game (now out of production), *Advocacy Challenge*, was featured on Radio National, and provided a fun way to learn about rights and services, and for consumers to have a go at getting on their soapbox.

Sandy is currently the Consumer Education Coordinator at the NSW Institute of Psychiatry (NSWIOP) and is responsible for writing and delivering workshops and courses for consumers and carers, which cover the general areas of consumer advocacy, self advocacy, recovery and safe storytelling. Sandy is also delivering consumer perspectives education at the Institute in postgraduate and other recovery courses, and is able to draw on her own experiences to shed light on a range of recovery themes, which can help mental health and other workers understand recovery principles and barriers to recovery - more clearly.

Sandy also provides education services to the non-government sector (NGO's); writes and reviews training, and works in collaboration with staff to improve training delivered to the community mental health sector.

Over the years Sandy has noticed a gradual change in attitudes towards consumer educators, and it is a long time since she has received any participant evaluations that say she is 'irrational'! However, there is a long way to go to gain acceptance, as occasionally there are people in attendance at workshops who are really confronted by the idea of lived experience trainers and lived experience perspectives – there is a 'glass ceiling' in terms of recognition of the central importance of consumer educators at, and across, every level of training pertaining to mental health education in Australia.

Sandy can be contacted by email: sandy.watson@nswiop.nsw.edu.au

or at home email: pogul.sm@bigpond.net.au

or by mobile phone on 0414 267 105



Kath Thorburn

Kath has worked in mental health for over 20 years, and currently working as an educator, consultant, and community mental health worker. In her work with both *inside out & associates Australia* and the *NSW Institute of Psychiatry*, Kath has been involved in the development of training that recognises the central role of lived experience knowledge in our understandings of and responses to extreme states and mental distress. At the Institute of Psychiatry, Kath co-coordinates (with Sandy Watson) two core subjects of the Masters of Mental Health (Adult) – ‘Facilitating Recovery’ and ‘Recovery Oriented Mental Health Practice & Systems’, as well as a range of short workshops on supporting recovery. These programs place lived experience knowledge at the centre of understandings and are delivered from a ‘both perspectives’ approach. *inside out & associates* (established by Kath, Sandy Watson and Michelle Everett) aims to provide opportunities for people to engage in critical conversations about current ways of understanding and responding to mental distress, and to develop more effective and helpful ways of working to support people who experience extreme states. Last month *inside out* held a conference, ‘More than medication – Critical conversations about medication, mental health & recovery’ and throughout this year has also worked with Mary O’Hagan, Rufus May and Peter Bullimore to promote recovery-oriented approaches to mental distress.

Contact: kthorburn@bigpond.com

Ann Tullgren:

Mad: I spent much of my twenties in psych hospitals.

Not Mad: I graduated with a degree in education in 1984.

Mad: The first year was undertaken from hospital and it took 6 years to complete a three year degree.

More Mad: These days can anyone stay on Sickness Benefit for over twenty years?

Not Mad: Graduated with Honours in Social Work in 1990. Degree completed on time.

Extremely Mad: The psychologist at Commonwealth Rehabilitation Service has said that I wasn't intelligent enough to get into university and too unstable to complete the degree.

Not Mad: I worked continuously as a social worker for 19 years. With Robert Bland and Noel Renouf I wrote 'Social Work Practice in Mental Health', Allen and Unwin 2009. Second edition to be written next year.

Mad: What is about menopause and bipolar? Retired from work.

Not Mad: A contented life with lovely, intelligent, funny Peter and three cats.

A Brief Overview of my teaching involvement

I have degrees in Teaching and Social Work and am no longer in the paid workforce. I am an Honorary Associate of the School of Sociology and Social Work at University of Tasmania (UTAS). This position recognises my ongoing association with the



University; it provides me with formal links within the School and staff privileges at the University Library. The Library privileges are particularly important for me.

I first began presenting to students in the early 1980's about my lived experience. Over the next few years had presented at all the Sydney Universities, TAFE and the NSW Institute of Psychiatry, for nursing, welfare, medical and social work students.

Now a resident of Hobart, I specialise in teaching in Social Work undergraduate and postgraduate courses, both at UTAS and University of Queensland (UQ).

My teaching is informed

- by my own experiences, critical reflection, and discussion with other consumers,
- by the literature (grey and white), and
- and underpinned by key AASW documents: Code of Ethics, AASW Practice Standard for Social Workers, and AASW Practice Standards for Mental Health Social Workers

Additionally, my preferred way of teaching is to take part in the full mental health subject (for Master of Social Work students this is 3x2 day weekends). In this way I can join in on discussions and informal talk. I always am asked to present 'my story'. This seems to be very important for the students. I acknowledge that many students will have their own experience of mental illness (themselves/family/friends). Always at the end of the class students will come up to me to talk about their own experiences. I often present other topics during the course eg history of madness, poverty and income support.

I have prepared handouts for students which are put up on the UTAS internal web, these include reading lists, listing of useful web sites, journal articles, personal accounts reflecting other diagnoses/experiences etc. I regularly update these. UTAS and UQ prefer digital resources not photocopied ones. I have begun using Power Point, finding that many students need visual as well as auditory input. A number of Master's students have told me that they have used my handouts and sections of our book (Robert Bland, Noel Renouf and Ann Tullgren 2009 *Social Work Practice in Mental Health*, Allen and Unwin) as the basis of presentations to work colleagues at team meetings and inservice.

Lyn Mahboub – Bio 2011

LYN brings a unique combination of experience to her work by way of formal academic training in Psychology and Communication & Cultural Studies, a past career in nursing and, both delivery of, and receipt of, mental health & addiction services. Her lived experience encompasses a range of experiences including 'mental illness' and addiction, and, as a parent of two adult children also diagnosed with mental health issues. These experiences provide her with an amalgam of both tacit and professional knowledge about working toward recovery across mental health and substance abuse. Lyn commenced her journey of recovery about 35 years ago



and is now an ex-consumer of services. Since beginning her journey, her knowledge of diverse healing and psychological and emotional healing and recovery modalities has grown and she has utilised them both personally and professionally.

Her interests in teaching and training span variety of recovery oriented topics directed to mental health professionals, families, consumers and the general public. Lyn currently works as a Consumer Academic for WA's *Curtin University* in Health Science the OT & Social Work Department, is the Recovery Advisor and Manager of the Training Department and the Hearing Voices Network at *Richmond Fellowship WA*, is the owner operator of *Caelan Consulting* her own Training & Consultancy business, is currently chairperson of the WA Mental Health Consumer Organisation *CoMHWA* (Consumers of Mental Health WA) and is part of the executive of EleMental WA's Recovery Network Cafe and Support Group.

Lyn believes deeply in the possibility of healing and recovery. Her life commitment is to social justice and psychiatric reform globally, and self-responsibility & self acceptance personally. Lyn's loves are her family and her pets and her work interests are Borderline Personality Disorder, Hearing Voices and personal/emotional recovery. Lyn has recently returned from the International Hearing Voices Conference in Italy where she also visited Trieste Mental Health Services which are considered the most avant-garde in the world and she was wowed in the extreme.

Lyn Mahboub BA (hons) Psych, Comm Cultural Studies
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Tania Lewis – Educator – Clinical and Lived Experience (B Ed & T)

I have been employed by Barwon Health for four years in a part-time role as a Mental Health First Aid (MHFA) trainer and in the past two years, as the Coordinator of the MHFA program.

During this time I have incorporated my lived experience of mental illness into the delivery of the course. As a result there have been times when workplaces have specifically requested that I be one of the facilitators due to the power of the lived experience in this training.

Whilst undertaking this role, I have, as part of the Mental Health Drug and Alcohol Service Education Team (MHDAS), also contributed to the undergraduate, graduate and post-graduate nursing training, again incorporating aspects of the lived



experience into the varied topics I have presented, including Major Mental Illness, Bipolar Disorder, Outcome Measures and Stigma.

I have also undertaken education and speaking engagements in the community delivering sessions to Deakin University Nursing students, TAFE Social Work students, Rotary Clubs, Probus clubs, community forums and small groups such as RSL ladies etc.

Since first joining Barwon Health MHDAS in 2005, management has discussed the possibility of developing a Consumer Educator role. This has recently been sanctioned and we are in the process of having the Position Description developed. The actual title is yet to be decided.

No specific education tasks have been agreed to but if I am the successful applicant for this position, I look like being involved in staff, consumer, carer and community training and education. I am currently involved in Outcome Measure training (as I was involved in the QUATRO Project in 2005 – 2006). I will be developing a consumer psychosocial education program which will be made available to consumers of the Barwon Health MHDAS.

I am involved in working parties looking at peer workforce development and implementing a recovery approach to care, advance care planning and I may be involved in training as a result of these initiatives.

I am currently assisting our Psychology Clinic to develop a peer support program for participants who have completed an anxiety and depression CBT course. I am helping to develop and will deliver some short session training about mental illness for young people in an alternative school.

This is a new role so I am interested to see what other Consumer Educator's are doing in their service.



Recovery Oriented Post Graduate Mental Health Education

Facilitating Recovery & Recovery Oriented Practice & Systems are core units of study in the Graduate Certificate, Graduate Diploma & Masters of Mental Health (Adult) at the NSW Institute of Psychiatry. These units were developed in 2004 and have also led to a revision of the postgraduate program overall to ensure it reflects the philosophy and principles of recovery.

Facilitating Recovery

(GCA004)

This unit aims to provide students with an appreciation of the diversity of personal recovery experiences, and to determine the characteristics of mental health practice that recognise, support and promote people's self-directed recovery from mental distress.

Topics covered are:

- **Conceptualising recovery** (process and paradigm, definition, principles, language, knowledge bases and evidence)
- **Historical context of recovery** (societal understandings & responses to distress over time, human rights agenda, recovery movement)
- **Lived experience of recovery** (personal narratives of recovery, the role of stories, hearing the story and clues to recovery)
- **Recovery concepts applied** (Workshop – applying recovery concepts in practice and services)
- **Recovery research** (recovery research and implications, recovery & evidence based practice in mental health)

Recovery Oriented MH Practice & Systems

(GCA005)

This unit aims to support workers to analyse current approaches to extreme states and distress, to consider how practice and services might better support recovery, and to initiate and support recovery oriented practices in their own services.

Topics covered are:

- **Introduction to conceptual framework & terminology** (Constructions of illness & distress, bodies of knowledge, terminology)
- **Making sense of the human experience of psychological distress** (diagnosis & values, philosophical, historical & contemporary influences)
- **Recovery oriented services & policy** (recovery-oriented services, peer support, role of community, other types of services)
- **Recovery-oriented practices** (principles & values, practices that promote recovery, relationship, supporting self-management)
- **Ethics & efficacy – perspectives from a recovery framework** (recovery-informed ethics, evidence-based practice & recovery)

Course Context

At the Graduate Certificate level students undertake both these units of study, as well as Population Health Approach to Mental Health Services (GCV001) and an elective of their choice. Those who move on to the Graduate Diploma level examine the relationship between trauma and mental distress and what it means to be trauma informed through two further core units of study. Students also undertake two further electives of their choice at this level. Research Methods is required for those continuing to Masters. The Masters level provides opportunities for students to undertake their own research or to further develop leadership, supervisory and therapeutic skills through the elective units.

Philosophy & implications

The design and teaching of the Facilitating Recovery and Recovery Oriented Mental Health Practice & Systems units of study aims to embody the principles of recovery. The implications for this are:

1. Safe space for participants to deconstruct and examine current approaches and practices, to question and to think about services from lived experience perspective;
2. Draw significantly on the lived experience knowledge base and provide opportunities for participants to explore and work with the tensions that can occur when we use both lived experience and professional knowledge to inform practice;
3. Opportunities for creativity and growth, and for mutuality through conversations, discussions and shared activities and experiences, to draw on the shared knowledge of the group to co-construct, to develop new knowledge (i.e. a parallel process); and
4. The two units are delivered from a 'both perspectives' approach – Sandy Watson & Kath Thorburn co-ordinate both units.

For more information contact kath.thorburn@nswiop.nsw.edu.au

About the Power On Program

'Through Power On I learned that I am 100% worthwhile and have every right to be here.'

About Women's Health West

Women's Health West (WHW) is a place based community organisation, within the western region of Melbourne. We work in partnership with women and a range of organisations to meet the social, emotional and physical health needs of women in our communities. Through advocacy and health promotion action we work to redress the gender and structural inequalities that limit our lives as women.

About Power On



Within this twelve week strength based program we endeavour to encourage women who experience mental illness to enhance their wellbeing, to identify and address their health needs and to also gain support from loved ones and service providers to do so.

The Peer Facilitator

One of the crucial aspects of the Power On program is peer education. A peer facilitators has been involved in every phase of the program; from research and development to delivery and evaluation. Power On is underpinned by feminist frameworks that recognise structural inequality and a social model of health. Recognising women as experts in their own health, this model acknowledges the value of women sharing their experiences and expertise with one another.

In this context a peer educator is a woman who has experienced mental illness. She generously shares her own life experience and her personal abilities, while encouraging the group to share with one another, in an effort to develop shared knowledge about enhancing wellbeing.

About the Program

In the beginning a peer facilitator and project worker consulted with over fifty women who have experienced mental illness, their loved ones and service providers across the Western Region. These conversations revealed ten themes that women identified as important to their health and wellbeing. The model has been developed to address the specific needs of women who experience mental illness. Strategies are included to actively engage women in a workshop style environment, and to encourage women to recognise their strengths and resilience, while tools to enhance wellbeing are explored together.

Power On



Positive Outcomes

An external evaluation found that women who participated in Power On overwhelmingly attributed positive changes in their attitudes and behaviours to the Power On program. It was revealed that they had taken on the learning objectives in a broader holistic way, rather than separating out the different topics. For example, the simple activity of going for a walk was understood as not only being useful for exercise, an opportunity to take time-out and relax but also for a way to reduce symptoms of menopause and to assist with positive thinking and the raising of self-esteem.

The Power On Story So Far

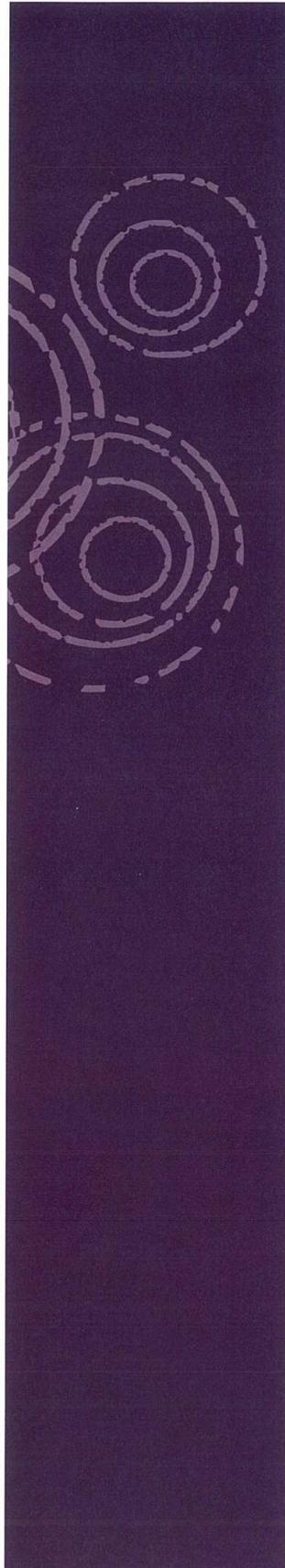
- Six mental health agencies in the Western Region of Melbourne were chosen to deliver the Power On program through an expression of interest process.
- Two Peer Facilitators are trained to deliver the Power On program.
- Thirteen staff members from Mental health agencies in the Western Region of Melbourne have been trained to facilitate the Power On program.
- The delivery of the Power On program in six mental health agencies in the western region of Melbourne will be complete in November 2009 with additional work occurring since that time.
- Women's Health West has trained facilitators and peer facilitators from Tasmania and Brisbane to implement Power On program.
- Power On is currently being implemented in numerous services across both Tasmania and Brisbane.
- A spin off of the Power On program designed for women who are carers of someone who experiences mental illness has been successfully implemented across the western metropolitan region of Melbourne.

Manual

A manual containing a guide to implementing the program, with training resources, including fact sheets, practical introductory notes, session plans with learning objectives and activity plans for each of the twelve modules has been developed. This manual is only available to those that have participated in the Power On Facilitator training, in order to ensure the integrity of this well researched model is maintained in its entirety.

Power On





inside out & associates australia

inside out & associates australia aims to promote opportunities for people who are interested in mental wellbeing and recovery through extreme emotional and psychological experiences / mental distress to better understand and respond to these experiences. This includes people who themselves experience mental distress, family members and friends, community support workers, mental health workers, general practitioners and psychiatrists, and anyone else who is interested in helpful approaches to living with and overcoming these experiences.

It is our belief that more helpful responses to those experiences labeled as mental illness or mental distress require authentic dialogue and real collaboration between all of us affected by these experiences. This includes those directly affected (through personal experience), those working to support people through these experiences, and the community as a whole. *inside out* draws on diverse perspectives about the nature of extreme psychological and emotional experiences and mental distress, believing that being open to diverse perspectives and ways of making sense of these experiences leads to more creative, inclusive and hopeful responses .

Why 'inside out'?

inside out recognises that the knowledge that comes from lived experience is key to better understandings and hence, better responses, supports and services that are more effective and helpful in supporting the recovery process. This is not to dismiss professional knowledge but to recognise that this knowledge is seriously limited when applied on its own. So lived experience knowledge is at the centre of every event, workshop, and forum that we offer, and this is reflected in our name – 'inside out'.

This also means that we aim to provide opportunities for people to engage in critical conversations about current approaches to understanding and responding to mental distress, what assists a person in their recovery and what might actually hinder this process. These critical conversations are essential if we are to really address the current shortfalls in service and system responses to distress. Recovery-based approaches to mental distress require us to examine and reconsider many of the assumptions, values and beliefs that have underpinned current approaches – to turn them 'inside out' so to speak – to be open to diverse perspectives and the range of other approaches that these offer.

Who we are

inside out & associates is Sandy Watson, Michelle Everett and Kath Thorburn, all of whom have extensive experience in teaching, writing and advocating for mental health system change in a range of roles and capacities.

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